

PUBERTY A GUIDE FOR TEENAGERS WITH AN AUTISM SPECTRUM DISORDER AND THEIR PARENTS



Acknowledgements

We would like to acknowledge the following organizations and individuals for their contribution to this project:

Latrobe University Project supervisor, Dr Diane Jacobs, Pauline Greenwood, Amanda Harris, Shelly Newton, and all the other parents of children with an ASD who generously shared their experiences but

wished to remain anonymous.

Written by:

Elizabeth Ford Gabriella Ptasznik Megan Blumberg Samantha Clayton Sara Beeching

Contents

Introduction	
Physical Changes- Information for Parents	2
What are the physical changes that occur during puberty? Talking to your child about puberty	2 2
Strategies to use when talking to your child about Puberty	3
Menstruation	
Strategies to prepare your daughter for her period	
Talking about ejaculation with your son	
Strategies to help your child with hygiene, including wet dreams Talking to your child about the importance of hygiene	
Strategies to help your child develop healthy hygiene	
routines	
Masturbation	
Physical Changes- Information for Girls	7
What is puberty?	6
Physical changes for girls	
Pimples	
Keeping clean	
Guide to showering	
What is a period	
Menstruation step by step Masturbation	
Guide to feminine hygiene	
Physical Changes- Information for Boys	
What is puberty?	
Physical changes for boys	
Pimples	
Keeping clean	
Different dreams	
My penis	
Voice changes	
Masturbation	
Step by step masturbation	12

Social Changes- Information for Parents	. 13
Social changes during puberty	
Strategies to help your child with social skill development	
Liking someone more than a friend	15
Strategies to help your child with romantic relationships	
Strategies to help your child deal with stalking behaviours	16
Touch Strategies to help your child deal with good touch	16
verses bad touch	17
Masturbation management and private verses public places	17
Strategies to help your child with private verses public places	
Social Changes- Information for Adolescents	
Liking someone differently to how you like a friend Signs that people show when they are your friend Signs of disinterest Stalking Defining touch Things that should be done in private with no other	20 20 21
people around (girls)	22
Things that should be done in private with no other	22
people around (boys) Masturbation management	22
Places that are okay to masturbate	23
Places that are not okay to masturbate Circle of friends activity	
Emotional Changes- Information for Parents	
Mood changes	26
Emotional awareness and regulation Strategies to help your child distinguish between different emotions. Regulating mood	28
Strategies for helping your child to regulate their mood	29
The Alert Program Understanding the emotions and perspectives of	
others	30

References	
Useful Contacts	
Increasing self-identity and self-esteem	
Managing Bullying	
Managing PMS	
Visual schedule: When you feel worried or nervous	
Visual schedule: When you get angry or frightened	
Others Managing Behaviour – Becoming angry	
Understanding the emotions and perspectives of	40
Understanding personal emotions – Sadness	43
Understanding personal emotions – Happiness	
Emotional Changes- Information for Adolescents	
Strategies to manage bullying	
Bullying	
Strategies to encourage self-identity and self-esteem	
Self-identity and self-esteem	
Medications to manage problematic behaviours	
Strategies for managing problematic behaviours	
problematic behaviours	37
Factors that may cause/worsen aggressive or	
Anger, aggression and problematic behaviours	
PMS	
Strategies for managing the emotional symptoms of	
disorder Girls- PMS and emotional changes	
situations for individuals with an autism spectrum	21
Strategies for parents to decrease anxiety-provoking	
Anxiety	
an autism spectrum disorder	
Strategies to help lowered mood in adolescents with	
disorder	
in individuals with an autism spectrum	
Possible behaviours reflective of symptoms of depression	
Depression Symptoms of depression in neurotypical individuals	
of other people's perspectives	
Strategies for increasing empathy and understanding	0.4

Introduction

This resource has been developed to provide parents, families, friends and caregivers information to assist teenagers with an Autism Spectrum Disorder (ASD), including Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) to recognize and manage the emotional, physical, and social issues that individuals diagnosed with an ASD will encounter during puberty.

An individual with an ASD may present with a diverse range of needs and skills. To produce a single resource to meet the needs of all individuals with ASD is not feasible. Therefore the information provided in this resource has been developed for both male and female teenagers who have a diagnosis of high-functioning autism spectrum disorder (HFASD), which is a diagnosis of ASD combined with a full scale intellectual quotient (FSIQ) greater than or equal to 70. However, information has been provided throughout the resource that can assist parents, families, friends and care-givers to tailor the resource to meet the needs of their teenager with ASD regardless of intellectual capacity.

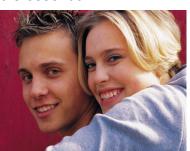
This resource has been designed to fill the gap that has been found to exist in current information and data. Investigations determined that the vast majority of the information available regarding changes in adolescence for the HFASD population was a) directed to professionals, parents, and care-givers of teenagers with an ASD, and b) discussed predominately physical changes and masturbation. In addition to investigating the available research literature, 13 parents of both male and female adolescents with a diagnosis of an ASD were interviewed. These interviews identified that parents had difficulty discussing puberty with their child, particularly the associated physical changes in a way that was meaningful to adolescent with an ASD. Parents also highlighted concerns regarding a focus on negative or problematic issues relating to puberty and adolescents with an ASD. All parents reported that being able to easily access an appropriate resource addressing the physical, emotional, and social changes would be of great benefit.

Information in this resource has been divided into three sections – Physical, social and emotional. Each section is prefaced for the parent or care-giver with specific details on each area of change during puberty, how to use the resource and adapt it to each teenager's specific needs and skill level. This is followed by information directed to the teenager with ASD, including visual schedules and descriptive stories.

PHYSICAL CHANGES-INFORMATION FOR PARENTS

The physical developments (sexual and body changes) that occur during adolescence occur alongside important psychological and social changes that mark this period as a critical stage towards becoming an adult (WHO,2011). The continuity of a familiar routine is vital for individuals with an Autism Spectrum Disorder (ASD) as they have particular difficulty coping with change. Thus, in order to relieve the pressure and stresses of understanding the changes that are taking place it is essential

to explain to your child the processes that are occurring during this time.



This material is designed to assist you and your child with...

- 1. Understanding how the body changes during puberty, including:
 - General body changes
 - Menstruation
 - Masturbation
- 2. Understanding good hygiene practice

What are the physical changes that occur during puberty?

During the pubertal years, a group of interacting hormones cause the changes of puberty. Puberty marks the period when the reproductive organs grow to adult size and start to become functional. This occurs due to rising levels of testosterone in males and oestrogen in females. Pubertal milestones occur in the same succession for all individuals; however, the age at which they occur often varies significantly (Marieb & Hoehn, 2007).

For males, the major event that proclaims the onset of puberty is the enlargement of the testes and scrotum between the ages of 8 and 14 (Marieb & Hoehn, 2007). Following this, the penis starts to grow and the young man will start to become sexually mature. This is frequented bv unexpected and often embarrassing erections and 'wet dreams' (sexually orientated dreams which cause the young man to emit semen during his *sleep*) as a consequence of surging levels of testosterone.

For females, the initial sign of puberty is evidenced by budding breasts which appear between the ages of 8 and 13 (Marieb & Hoehn, 2007). This is followed by armpit and pubic hair. The young woman's first period may occur approximately two years later.

Talking to your child about puberty

Typically, the time at which an adolescent, even without an ASD, goes through puberty can be stressful for all family members. Although, when a child has an ASD, these stressful times are compounded and may become more complex. (Artclesbase 2008).

As a parent, it is common to wonder when the appropriate time is to commence discussions regarding puberty with your child. However, children with an ASD commonly need a longer period of time to comprehend and accommodate themselves to any changes that occur in their lives. Thus, according to your child's specific personality, you will need to decide how much preparation time he/she needs to understand the changes associated with puberty (The National Autistic Society, 2011).

To ensure that your child is adequately prepared for the changes that will occur/ are occurring, you may inform your child from a young age that you are always available to talk about any auestions he/she might have regarding their body. This will serve to highlight that pubertal changes are part of a normal occurring physical process and he/she should not be ashamed. These preparatory conversations will also help maintain your child's self confidence (The National Autistic Society, 2011).

Strategies to use when talking to your child about puberty

- Expect your child to ask a variety of awkward 'why' questions. It is particularly important with children with an ASD that you try and stay patient and sensitive when answering their questions. (National Children's Bureau, Sex Education Forum, 2003).
- Always be honest with your child. It is also okay to just say 'I don't know' or 'how about we look it up together' (The National Autistic Society, 2011).
- Make sure you are 100% certain with your answer as you may confuse your child even more by not providing a clear and accurate response (The National Autistic Society, 2011).

- If you notice that your child frequently asks questions at inappropriate times, it may be helpful to establish a fixed response, which can be utilized by all family members. For example. response may а include: 'That's а fantastic question, but let's talk about it when we are at home' (National Children's Bureau, Sex Education Forum, 2003). Ensure that you do revisit your child's question when you return home, otherwise your child may be hesitant to ask you questions in the future (The National Autistic Society, 2011).
- Always answer in a positive tone so that your child feels comfortable to approach you again (Autism Society of America, 2011).
- When explaining different female and male body parts be sure to use the correct medical terminology as abstract concepts are particularly difficult for many individuals with an ASD to comprehend (Autism Society of America, 2011).
- Ensure that you frequently remind your child that he/she should be happy with their body.
- It is helpful to view puberty as just another step of your child's developmental process.
 Welcome and celebrate this time and proceed forward in your future together (Autism Society of America, 2011).

MENSTRUATION

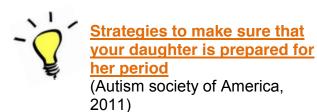


Menstruation (when a girl gets her period) is the principle stage of female puberty. It is one of several physical signs that a girl is developing into a grown woman. Your daughter may be excited or even feel afraid or anxious prior to getting her first period. During adolescence, most girls

have very little understanding of how the reproductive organs function which causes this change to be even more confusing (Kids Health, 2011).



It is important that your daughter is aware and prepared for her period.



- Use red food dye in your daughter's underwear to mimic what the blood may look like when she does begin to get her period.
- You may like to describe a sanitary napkin as a very large bandage.
- Use the visual aid provided to describe the steps involved in changing a sanitary pad.
- A female should model the steps involved in wearing and changing a sanitary pad.

- Make a mark on your daughter's underwear to indicate exactly where the sanitary pad should be placed in her underwear.
- Go to the supermarket with your daughter and ask her to choose a variety of different sanitary pads with you.
- Watch a video about menstruation online; <u>http://kidshealth.org/teen/sexual</u> <u>health/girls/</u>
- When your daughter gets her first period, plan a party to celebrate her entry into womanhood.

Talking about ejaculation with your son

As mentioned earlier, one of the main indications that your son is going through the puberty is the noticeable enlargement of the scrotum and testicles (Marieb & Hoehn, 2007). As your son progresses through puberty, the size and shape of his penis will develop along with his sexual maturity (Autism Society America, 2011). During puberty, your son may have erections at peculiar or unexpected moments and will also begin to ejaculate semen. Initially, many boys are unsettled when they see the appearance of semen for the first time, however you should reinforce to him that this is a normal step of puberty and will eventually stop (Autism Society America, 2011).

While talking to your son about erections may be an awkward and uncomfortable topic to approach, especially if your child has an ASD, it is imperative to explain these events prior to them occurring.

<u>Strategies to help your</u> child with hygiene, including wet dreams

- The majority of Individuals with an ASD have greater strength in learning with visual material. Therefore, you may find it useful to take pictures that relate to some of the steps that are included in the visual aid in order to ensure that the aid is as familiar and effective as possible. Once you have taken the appropriate photo you may want to stick them beside the steps already provided. For example, it may be useful to take a photo of your child putting on deodorant or washing their face.
- Use the tailored tales provided in this resource to discuss the basic physical changes that occur with puberty.
- Remind your son that ejaculation, 'wet dreams' and masturbation are all perfectly normal (Autism Society America, 2011).
- When your child has an erection or a 'wet dream' it is likely that he is unaware of what is happening to him. Thus, it is important to not overreact or underreact (Autism Society America, 2011). When this occurs, change the sheets together and use the tailored tales provided to explain what has happened.

- Ensure that you use a calm and sensitive voice when explaining what has happened (Autism Society America, 2011).
- Relate 'wet dreams' and erections to the other changes he is noticing with his body during this time. Remind him that all these changes are normal and help him grow into a man (Autism Society America, 2011).

Talking to your child about the importance of hygiene

Accompanying the aforementioned physical pubertal changes that occur to both young females and males comes new and often unfamiliar daily hygiene routines. Thus, educating adolescents about hygiene skills is pivotal as they learn the importance of modesty, responsibility and self-care. This is especially crucial throughout puberty as cleanliness is a contributing element to their health and selfconfidence.



Establishing strong hygiene routines are a vital life skill. However, for many individuals with an ASD, developing these habits may be complicated and difficult. Moreover, children who do not have an ASD are naturally unreceptive to a child with poor hygiene. Consequently, your child with an ASD may experience further social ramifications, such as a child teasing your son/daughter that he/she smells bad. It is for these reasons that ensuring your child forms healthy hygiene routines is critical.



- Use the visual aids provided to help show your child a healthy hygiene routine in a sequential format.
- Model the steps of the visual aid for your child.
- Place the visual aid in the location where they are most likely to be used. For example; place the showering visual aid on the bathroom wall or on the outside of the shower.
- Associate hygiene behaviours and routines to something concrete. For example. highlight the significance of personal hygiene to your child by explaining that in order for him/her to have friends. he/ she needs to make sure they stay clean (American Autism Society, 2011). You may continue by stating exactly what needs to be done for this to occur. For example; brush your teeth every morning and before you go to bed, have a shower every day and wear deodorant.
- To ensure that your child changes their behavior or forms an ideal behavior, highlight to your child why they should care about their personal hygiene. This will give them motivation to want to change. For example, relating staying clean

to having friends may encourage your child to focus on complying to a healthy hygiene routine (American Autism Society, 2011).



• Be sure to be specific and precise when communicating with your child. For example, reiterate that if your child smells like sweat, people will not want to be around him/her (American Autism Society, 2011).

MASTURBATION

А behavioural result of surging testosterone and oestrogen levels in females voung males and is masturbation. Don't be alarmed if your adolescent child masturbates as it is a perfectly normal and expected behaviour.

It is best to assure him/ her that this is normal and encourage him/her to masturbate in a private place. If you notice that your adolescent child is masturbating constantly you should seek help from your family doctor.

Additional strategies and information regarding how to talk to your child about masturbation are provided in the social section of this resource. When explaining masturbation to your child use the tailored tales provided in this section.

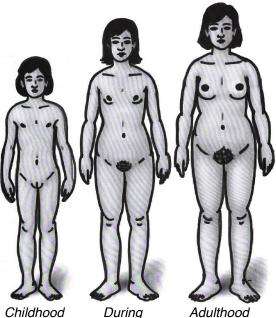
PHYSICAL CHANGES-INFORMATION FOR ADOLESCENT GIRLS

WHAT IS PUBERTY?

I once was a child but now I am growing up. My body is changing as I become an adult, this is called puberty. Pubertal changes are different for boys and girls.

PHYSICAL CHANGES FOR GIRLS

I was once a baby, then I was a girl. I am now an adolescent, which means I am becoming a woman and I will notice some changes with my body.



Childhood

Adulthood

(!)Pubertal changes may occur at varying rates and times. Your child needs reassurance that these changes are normal and they may not develop at the exact same rate as their friends (Better Health, 2011)

Puberty

BODY CHANGES

My body shape will change.

HEIGHT

I will grow taller

HIPS My hips will widen

GROWING BREASTS

I will notice small bumps underneath my nipples which may feel slightly tender. My breasts will continue to grow and I will need to wear a bra. A bra will support my breasts.

GROWING HAIR

I will grow hair in places where there was none.

I will start to grow hair on my private areas and under my arms. In the beginning my hair may be thin and soft but as I grow older it may get thicker. I may want to shave the hair under my armpits. This may help me in keeping this area clean.

PIMPLES

When I am growing up I may notice red spots on my face, these are called pimples. I can wash my face to keep my skin clean. I may need to put some cream on my pimples, this may feel different, that is ok. It is best if I leave these spots to go away.

KEEPING CLEAN

I will notice that I am sweating more than I use to because my sweat glands are becoming more active. Sweating is when my body releases small amounts of fluid in order to make sure I am not too hot. I may notice this when it is hot outside, when I am nervous or when I am playing sport. Most people dislike the smell of sweat, so I need to make sure that I wash myself every day. After my shower, I should use deodorant under my arms. This may feel strange and different, that is ok.

Deodorant will help stop my body smelling badly. I can also carry deodorant in my bag just in case I feel that I am sweating too much and I am starting to smell.

STEP BY STEP IN THE SHOWER FOR GIRLS

- 1. I will wash my face, arms, stomach, feet and legs with soap and a face-washer
- 2. I will wash under my armpits with soap
- 3. I will wash around my vagina with soap
- 4. After the shower:
 - I will dry my armpits with a towel
 - I will dry my vagina with a towel
 - I will put deodorant under my armpits
- 5. I will get dressed into clothes that are clean.
- The above routine may be adapted for your child specifically. For example, if your child performs other routine based activities during/ after her shower time ie. Using pimple cream or putting her towel in the laundry, this may be added.

You may find it useful to take pictures that relate to some of the steps that are included in the visual aid in order to ensure that the aid is as familiar and effective as possible. Once you have taken the appropriate photo you may want to stick them beside the steps already provided. For example, it may be useful to take a photo of your child putting on deodorant or washing their face.

WHAT IS A PERIOD?

As my body changes and I become a woman I will get my period.

A period is also known as menstruation. Most women have a

period every 28 days, sometimes it may be sooner or later, this is ok. When I get my period blood comes out through my vagina. A few days before I get my period I may feel more upset about things; I might feel angry, I might feel sad, I might feel frustrated or I might feel other emotions.

Feeling this way is normal and usually stops when my period starts.

My breasts and stomach may feel sore at this time. This is normal. Placing a hot water bottle on my stomach and having some pain relief medication may help me feel less sore.

If your child experiences any of these emotional changes mentioned above, please refer to the "emotional" section of this resource. If your child experiences pain, please amend as appropriate, e.g. heated wheat bag for hot water bottle etc.

I may have my period for 4 to 7 days. It may be shorter, that is okay. If it is longer than 7 days I will talk to an adult that cares about me. When I first get my period it may only come every few months but as I get older it may come more regularly (Better Health, 2011).

I will need to use a pad or a tampon so my clothes don't get stained. These come in many different shapes and sizes.

Periods are private. I may want to talk about my period with my good friends and parents. This is ok. I should only talk to these people about my period.

MENSTRUATION STEP BY STEP:

I will change my pad at least every four hours.

I will wash my hands.

I will go to the toilet and close the door. I will pull down my underwear and sit on the toilet. I will take the dirty pad off my underwear.

I will wrap the dirty pad up in toilet paper.

I will put the dirty pad in the bin.

I will un-wrap a clean pad.

I will take the sticky strip off.

I will stick the clean pad in my underwear.

I will wipe my vagina with toilet paper.

I will pull up my underwear.

I will wash my hands.

If your child prefers to use tampons, you may create your own similar step by step guide in order to assist your child with this process. Assure your child that everyone is different and every girl's period may

be longer or shorter than her own.

It may be useful to accompany this step by step guide with relevant pictures or photos, of your daughter's choice to practically guide her through this process.

MASTURBATION

As my body changes, I will start to feel new sensations that feel nice. I may touch parts of my body because it feels good. This is okay. This is private and should be done only in a private place. For example; my bedroom with the door closed or my bathroom with the door closed. Other people may dislike me talking about masturbation, so I will keep it private.

STEP BY STEP MASTURBATION FOR GIRLS:

- 1. Close my room door
- 2. Close my blinds
- 3. Touch myself where it feels nice
- 4. Clean my hands
- 5. Go out of my room

Although I enjoy touching myself and sometimes may enjoy others touching

me too, I need to make sure that the person I am touching likes it as much as I do.



Additional information regarding good touch and bad touch is included in the social section of this booklet.

PHYSICAL CHANGES-INFORMATION FOR ADOLESCENT BOYS

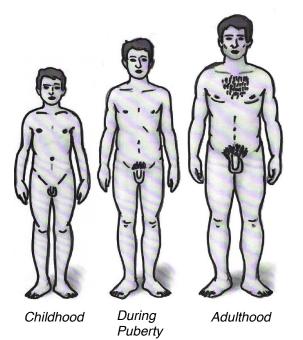
WHAT IS PUBERTY?

I once was a child but now I am growing up. My body is changing so I can become an adult, this is called puberty. These changes are different for boys and girls.

Pubertal changes may occur at varying rates and times. Your child needs reassurance that these changes are normal and they may not develop at the exact same rate as their friends

PHYSICAL CHANGES FOR BOYS

I was once a baby, then I was a boy. I am now an adolescent becoming a man and I will notice some changes with my body.



Pubertal changes may occur at varying rates and times. Your child needs reassurance that these changes are normal and they may not develop at the exact same rate as their friends (Better Health, 2011)

<u>HEIGHT</u>

I will grow taller

MUSCLES

I will grow muscles in my arms, legs, chest and all over my body. This will make me stronger and heavier.

GROWING HAIR

I will grow hair in places where there was none. I may start to grow hair on my face, private areas, under my arms, on my back and on my legs. The hair on my body may grow thicker as I get older.

The hair on my face may feel strange, this is ok. If it is uncomfortable I can talk to mum or dad about shaving with a razor and cream or with an electric razor. If I don't shave the hair on my face I may grow a beard and moustache.

PIMPLES

When I am growing up I may notice red spots on my face, these are called pimples. I can wash my face to keep my skin clean. I may need to put some cream on my pimples, this may feel different, that is ok. It is best if I leave these spots to go away.

KEEPING CLEAN

I will notice that I am sweating more than I use to because my sweat glands are becoming more active. Sweating is when my body releases small amounts of fluid in order to make sure I am not too hot. I may notice this when it is hot outside, when I am nervous or when I am playing sport. Most people dislike the smell of sweat, so I need to wash every day. After my shower, I should use deodorant under my arms. This may feel strange and different, that is ok. Deodorant will help stop my body from smelling bad. I can also carry deodorant in my bag just in case I feel I am sweating too much and am starting to smell.

STEP BY STEP IN THE SHOWER FOR BOYS

- 1. I will wash my face, arms, stomach, feet and legs with soap and a face-washer
- 2. I will wash under my armpits with soap
- 3. I will wash around my penis with soap
- 4. I will pull back the foreskin gently and clean under it
- 5. After the shower:
 - I will dry my armpits with a towel
 - I will dry my penis with a towel
 - I will put deodorant under my armpits
- 6. I will get dressed into clothes that are clean.
- The above routine may be adapted for your child specifically. For example, if your child performs other routine based activities during/ after his shower time ie. Using pimple cream or putting his towel in the laundry, this may be added.

You may find it useful to take pictures that relate to some of the steps that are included in the visual aid in order to ensure that the aid is as familiar and effective as possible. Once you have taken the appropriate photo you may want to stick them beside the steps already provided. For example, it may be useful to take a photo of your child putting on deodorant or washing their face.

VOICE CHANGES

My voice may change. It may get deeper and start to sound more like

my dad's, uncles, or grandfather's voice. When my voice first starts to change, it may sound squeaky or croaky. This is normal. Later my voice may sound like a man's voice sounds.

MY PENIS

My penis will grow longer and thicker. My testicles (balls) will also get bigger. I will begin to have erections. This means my penis will get larger and harder. Erections may happen at any time, this is normal, all my male friends may also have this happen. I may need to cover my erection. Other people would prefer it if I did this.

Ensure that your child understands that this may occur at any time or place. However, he should know that this is normal and is expected (Better Health, 2011).

DIFFERENT DREAMS

When I am sleeping I may have a dream and when I wake up I might find that my sheets are sticky and wet, this is called a wet dream. When I have a wet dream I should always wash my testicles (balls) and penis when I wake up. Wet dreams happen to lots of boys and men.

Ensure that your child understands that this is normal and that when this occurs they know that their bedding and clothing should be cleaned. This may be added into their hygiene routine.

MASTURBATION

During these changes I will get new sensations which feel nice. I will get more erections and will want to touch my penis and other parts of my body because it feels good. When I touch myself I need to be alone and in a private place with the door closed.

Physical Changes

When I touch myself, semen might come out of my penis. This is normal. I should use tissues to clean myself and throw them in the bin when I am finished and then wash my hands.

STEP BY STEP MASTURBATION FOR BOYS:

- 1. Close my room door
- 2. Close my blinds
- 3. Touch myself where it feels nice
- 4. Clean my penis with tissues
- 5. Throw the dirty tissues in the bin
- 6. Clean my hands
- 7. Go out my room

Although I enjoy touching myself and sometimes may enjoy others touching me, I need to make sure that the other person that I am touching likes it as much as I do.

Additional information regarding good touch and bad touch is included in the social section of this booklet.



You may find it useful to take pictures that relate to some of the steps that are included in the visual aid in order to ensure that the aid is as familiar and effective as possible. Once you have taken the appropriate photos you may want to stick it beside the steps already provided. For example, it may be useful to take a photo of your child's room door or your child washing his hands.

SOCIAL CHANGES-INFORMATION FOR PARENTS

The transitions and changes that occur during puberty can be a difficult time for all adolescents and can be especially difficult for children with an ASD for various reasons. A number of changes will take place; in addition to the physical changes previously discussed in this resource. adolescence is a time of social change. Most children with an ASD have difficulty adjusting to this transformation (Teens Health, 2011). Thus, the continuity of a familiar routine is vital. In addition, explaining the changes that will occur will make this time of development easier. Using this resource will assist adolescents with understanding and coping with the changes that are occurring in their evolving bodies and minds.

This material is designed to work towards your child understanding the following objectives...

- 1. Liking someone differently to how you like a friend
- 2. Signs of disinterest
- 3. Defining touch
- 4. Who is appropriate to touch?
- 5. Things that should be done in private for both girls and boys
- 6. Appropriate places to Masturbate
- 7. Circle of friends activity

Note: As there is a wide range of intellectual and communication levels between individuals with an ASD, the information and strategies suggested within this resource will need to be customized to ensure that they can be easily understood by the individual. For example, the vocabulary chosen, and the length of information contained in tailored tales or visual aids (e.g. charts, schedules) can be altered depending on the level that the individual's parent or guardian feels will be most appropriate.

SOCIAL CHANGES DURING PUBERTY

Individuals with an ASD typically exhibit difficulty with social skills, thus impacting upon their ability to establish meaningful social relationships with others (Morris, 2008). For example, many adolescents with an ASD may have difficulty simply having a conversation and understanding how others think and feel (Workforce Council, 2011).

Please note: Not all adolescents with ASD will have difficulty building and maintaining relationships. This may not apply to your son/daughter.

As a parent of an individual with an ASD, it is normal for you to have concerns regarding your child's social functionina. particularly durina puberty. lt may be especially frustrating for you when you notice that your child is trying to create and maintain friendships, but is often having difficulties (Workforce Council, 2011). During puberty, these social challenges are likelv to be exacerbated as new social skills are learnt during this time of development (Morris, 2008). It is important for your child to have a solid foundation of skills throughout puberty, such as knowledge of private versus public places, liking someone differently to liking a friend, signs of disinterest, signs of being more than a friend, good touch versus bad touch, and knowledge of their circle of friends.

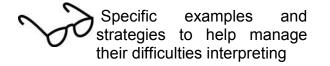


SOCIAL INTEREST

You may notice that your child has difficulty maintaining eye contact, initiating interactions, and inferring the interests of others. These characteristics are likely to impact the development and maintenance of meaningful and rewarding personal relationships (Dodd, 2005).

Many individuals with an ASD desire social involvement and interaction with others, however they may display reduced capacity to interact effectively (Dodd, 2005) as they have difficulty using their communication and social skills in the most appropriate and effective manner (Nichols, Moravcik & Tetenbaum, 2009).

Children with an ASD may dominate the conversation by not allowing others to interject or they may talk about things that only interest them. These issues may further compound the difficulty an individual with an ASD typically displays in forming meaningful relationships with others (Betts & Patrick, 2008).



others will be discussed later on in this section. Signs of interest and signs of disinterest can be explicitly taught to children with an ASD using lists, examples, and pictures.

Strategies to help your child with social skill development

Teach your child about body language and social cues.

- Teach possible beginnings and endings to conversations and topic initiation.
- Visual support strategies can be used for turn-taking and topic maintenance, for example, a 'my turn' card can be passed back and forth between communication partners.
- Find special interest groups for your child to discuss topics that they are passionate about with other individuals also interested in the topic.
- Formally invite other children to your home to encourage social interaction.
- Use tailored tales to teach your child socially appropriate behaviors.
- Role playing various social situations can be effective in teaching your child appropriate social responses.
- Videotaping appropriate or inappropriate behaviors can assist in teaching your child to respond appropriately in social situations.
- Social goals should be based on the amount of interaction and

exposure to social situations that your child feels comfortable with.

LIKING SOMEONE MORE THAN A FRIEND

Individuals with an ASD may have trouble developing relationships (Attwood, 2009). One of their main difficulties is being able to identify how someone else may be feeling (Nichols, Tetenbaum, Moravcik & 2009). Usually, individuals develop this skill naturally through having practice and experience with family members and friends. These acquired skills naturally assist the development of a romantic relationship. However, children with an ASD may have limited social skills, poor communication skills and a communicate reduced ability to emotions. Therefore, their capacity to maintain long term romantic а impacted (Attwood, relationship is 2009).

Even though the adolescent with an ASD may have difficulty understanding others emotions and communicating their feelings, it is still possible for them to develop a romantic relationship. However, it is likely to be more difficult for them than it is for others.

When developing a romantic relationship, it is important that your child understands the importance of respect.

Children with an ASD may have particular difficulty with selfunderstanding (Attwood, 2009). Adolescents with an ASD have difficulty understanding that expressing deep romantic feelings for somebody can sometimes be embarrassing (Nichols. Moravcik & Tetenbaum. 2009). Typically, teenagers are subtle about their feelings and romantic interests. Problems will arise if teenagers with an ASD do not use subtlety when expressing their feeling. Consequently, other teenagers may react badly (Attwood, 2009).This may be embarrassing and cause teasing amongst friendship groups (Attwood, 2009).

Children with an ASD find it challenging to build and maintain romantic relationships as they are likely to have limited social and communication skills.

Strategies to help your child with romantic relationships

- Explicitly teach your child how others may be feeling. This includes explaining that most teenagers are embarrassed about having a crush or developing romantic relationships.
- In order to form solid social skills, it is crucial to assist your child in developing friendship skills from a young age. In addition, this will also aim to improve self-esteem. Thus, assisting them in developing romantic relationships appropriately in the future.
- It may be useful to use the tailored tales provided.
- It is beneficial to use pictures and videos in order to provide an example of appropriate relationship skills.
- It may be a fun activity to role play several situations whereby your child can practice their relationship skills. Acting these skills out with yourself or another family member

will serve to further consolidate their experience and skills when next striking up a conversation. For example, pretend to be the boy/girl your child has a 'crush' on while your child practices conversing with you appropriately.

STALKING

As mentioned above, children with often an ASD have trouble perceiving verbal and nonverbal communications from others (Mesmere, 2007). If your child has perceiving others, trouble it is possible that they may make poor judgement decisions such as touching someone who may not want to be touched, following someone when they may not want to be calling followed, or someone continuously when they may not want to be called (Legal Aid, QLD, 1997). This can be misinterpreted by others as stalking.

Amongst all the social skills required throughout puberty, appropriate boundaries are a crucial skill. Teaching your child these types of boundaries will ensure fluid social encounters in the future, avoid embarrassing situations and will prevent them from getting into dangerous circumstances. Personal boundaries are frequently a problem for children with an ASD, particularly during puberty (Betts & Patrick, 2008).

Usually, children learn appropriate and inappropriate behaviours through discussion and social situations. However, children with an ASD need a more precise and clearcut explanations (Betts & Patrick, 2008).



It is important that your child understands boundaries, *including types of behaviours that may be seen as stalking.*

Strategies to help your child deal with stalking behaviours

- Your child may need to be constantly reminded of appropriate and inappropriate behaviour after each social situation they encounter.
- You may want to provide explicit and visual instructions, including appropriate and inappropriate behaviours to your chid.
- It may be useful to utilise the tailored tales provided in this resource to assist you in describing these behaviours to your child.
- Pictures and videos may be beneficial in order to teach appropriate and inappropriate behaviours such as stalking.

TOUCH

It is important to explicitly teach the difference between good touch and bad touch to your adolescent with an ASD.

Good touch is something that friends and family may do to show their affection for one another. These touches may include; a handshake to say hello, a hug or a kiss. A bad touch is something that feels

wrong or uncomfortable, such as a stranger asking for a kiss (Goulstein, 2010).



It is important that your child understands the difference between good touch and bad touch.

Strategies to help your child deal with good touch verses bad touch

- The difference between good touch and bad touch should be discussed.
- It is important to explain to your child that a touch may be a good touch for one person, but the same touch may be a bad touch for someone else. For example, one person may like to be tickled (this is a good touch), whereas someone else may not enjoy being tickled (this is a bad touch).
- Explicit and visual instructions including appropriate and inappropriate touching needs to be given to children with an ASD. For example shaking someone's hand to say hello can be shown as a good touch. Whereas you may show videos to highlight the effects of a bad touch. For example, someone being tickled when they do not want to be.
- Modelling appropriate touching with peers and adults has also been reported to be helpful in establishing personal boundaries. For example giving your child a kiss goodnight

Masturbation Management and Private verses Public Places

Masturbation refers to the sexual stimulation of one's genitals, touching or rubbing private areas for sexual pleasure. It is normal and healthy to

explore one's own body (Better Health Channel, 2011). Many males begin masturbating between the ages of 13 and 15 years (Better Health Channel, 2011). The onset among female masturbation occurs more gradually. These statistics are for all children including individuals with an ASD (Morris, 2008).

Masturbation is an uncomfortable topic when discussed with anyone, including parents, friends, or within someone's own family.

As your child grows and develops, they will begin to discover their bodies. As Sex hormones become active during puberty; many adolescents begin to have pleasurable and excited feelings about their bodies. It is important that you understand that your child with an ASD, like all children may be attracted to and interested in other people's bodies during this pubertal transformation. It is important for you to understand that these feelings are normal. They may be difficult for your child to describe and they may be difficult for you to describe to your child. It is essential that you explain to your child that these feelings will happen at different times and in different ways for all boys and girls (Morris, 2008).

Your child should not feel embarrassed about any sexual feelings they may have. The sexual feelings of adolescents with an ASD are no different to the feelings that other adolescents feel during this time. (Haywood & Saunders, 2010).

typically Usually, with parents developing adolescents may not need to discuss the topic of masturbation with their son or daughter, because their son or daughter is able to understand the appropriate social cues associated with these behaviours (Haywood & Saunders. 2010). Typically, adolescents understand that masturbation is a private behaviour to be done in a private place. In addition, they commonly understand that these matters should not be discussed with everyone or in a public area. In comparison, individuals with an ASD may be unaware of the reactions of others. They may continue to discuss an uncomfortable topic despite the negative reactions of others (Morris, 2008). They might naturally start touching themselves in public and may not realize that it is wrong (Haywood and Saunders, 2010). This is certainly a pivotal topic to address with your child.

Possible reasons for inappropriate masturbation include:

- No structured routine and time made available for masturbation
- Not enough education about privacy
- Not enough opportunity during the day for privacy
- There may be no locks on bedroom doors to provide privacy
- Parents or siblings and other residents may not respect the privacy of another person's bedroom

It is important that your child understands public versus private places.

- Strategies to help your child with private vs. public places

- It may be useful to utilise the tailored tales in this resource to assist you in describing private and public places to your child.
- Pictures or photos can be used as a way to visually demonstrate the difference between private and public places
- It may be beneficial to use videos in order to inform your child about the importance of privacy.
- Compare masturbating to another experience that he/she does by himself/herself in private, such as taking a shower or using the restroom. It is essential to teach private and public places when your child is young.
- It is important to teach your child private versus public places. Private places should be described as one's bedroom or bathroom, where he/she is alone. Contrastingly, a public place should be explained as a place where other people reside.
- Teaching your child appropriate times and places to masturbate will be beneficial in order to ensure that he/she does not begin masturbating in public.
- You may wish to teach your child that private parts of the body are those we keep covered in public places. Moreover, it may be helpful to explain that touching private parts of the body is only done in a private place with the door closed.

- You may wish to play a game in order to consolidate your child's ability to differentiate between private and public places. For example, in your house, instruct your child to run to a private/public place and hide. You may then go and find him/her. Once you find he/she is found, ask him/her why that particular place was chosen as a private or public domain.
- You may find it useful to take • photos that relate to your child's own private and public places. This will ensure that the aid is as familiar and effective as possible. Once you have taken the appropriate photo you can stick them beside the lists of private and public places that have already been provided. For example, it may be useful to take a photo of your child's bedroom, or a familiar shopping centre.

SOCIAL CHANGES-INFORMATION FOR ADOLECENTS

LIKING SOMEONE DIFFERENTLY TO HOW YOU LIKE A FRIEND

A friend is someone I know very well. My friends care about me and I care about them too. I trust my friends and they trust me. Sometimes I may want to have a special friendship with someone. I may start to feel different about them. I may not be able to stop thinking about them. I may think this person is attractive and they are not related to me. I may like them to be my boyfriend / girlfriend. It is okay to feel this way but they may not always feel the same way about me. Sometimes it is hard to know if someone feels this way about me. I should know that just because someone is being friendly to me does not mean that they like me like a special friend and want to be my boyfriend / girlfriend.

SIGNS THAT PEOPLE SHOW WHEN THEY ARE YOUR FRIEND:

- Smiling
- Talking to me
- Asking me lots of questions
- Spending time with me
- Caring about me
- Leaning closer to me
- Touching my hair
- Touching my face



If people show me these signs then it is appropriate for me to continue talking to them.

If there are any other signs of interest you feel appropriate to mention, you may add them to the list above.

SIGNS OF DISINTEREST



- Looking away
- Moving away
- Looking unhappy
- Turning away from me
- Crossing their arms
- Doesn't listen to me

If people are showing me these signs I should stop talking to them and leave them alone because these people are not interested in talking to me.

If you have any other signs of disinterest that you feel are
appropriate, you may add them to the list above.

STALKING

Stalking is when I follow someone around, to their house, to school or any places they often go (Farlex, 2011).

If someone is stalking me, they will constantly;

- Follow me
- Comes over to my house over and over again, even though I don't want them to
- Call me or speak to me over and over again, even though I don't speak
- Send me messages over and over again, even though I don't send messages back to them
- Make me feel uncomfortable

If someone is doing this to me, it is not right and I should tell a grown up.

Sometimes I may like someone and feel like I want to spend a lot of time with them but they may not feel the same way about me because they may not want to spend time with me like I want to spend time with them.

They may not return my calls or invite me over to their house. I should not go over to their house if I am not invited.

If I do go to their house or follow them, that would be wrong.

DEFINING TOUCH:

Good touch and bad touch:

Good touch is something that makes us feel happy and comfortable. For example; When I hold hands with my friends When I hug my parents When my teacher pats me on the back for doing great work Shaking somebody's hand when I meet someone new

Bad touch is something that make me feel confused and uncomfortable For example;

When someone I don't like more than a friend touches me in my private areas

Someone hitting me

When someone touches me and makes me feel unsafe or uncomfortable

When someone kisses me when I don't want them to

It makes a difference **WHO** is giving us the touch

Hugs, kisses and touches from people I know and love can be **GOOD** touches.

BUT the same touches from people I don't know and love can be **BAD** touches.

Although I enjoy touching myself and sometimes may enjoy others touching me, I need to make sure that the other person that I am touching likes it as much as I do.

Please note, if you know your child does not feel comfortable being 'pat on the back or hugged' customize the tailored tales to be appropriate for your child specifically.

THINGS THAT SHOULD BE DONE in private WITH NO OTHER PEOPLE AROUND (GIRLS):

- Pee or Poo
- Having a shower
- Picking your nose
- Scratching private parts
- Changing your pad (a pad is what I put on my underwear when I have my period. This stops my clothes from getting dirty when I have my period.)
- Masturbating
- Changing clothes

If your child has a co-morbid physical disability and this list is not appropriate, you may alter it accordingly. Moreover, if you notice that your child is exhibiting any other inappropriate behaviours these should be added to this list.

THINGS THAT SHOULD BE DONE in private WITH NO OTHER PEOPLE AROUND (BOYS):

- Pee or Poo
- Having a shower
- Picking your nose
- Scratching private parts
- Adjusting private parts
- Masturbating
- Changing clothes

If your child has a comorbid physical disability and this list is not appropriate, you may alter it accordingly. Moreover, if you notice that your child is exhibiting and other inappropriate behaviors these should be added to this list.

MASTURBATION MANAGEMENT

As my body changes, I will start to feel new sensations that feel nice. I may touch parts of my body because it feels good. This is okay.

I should masturbate in private places so that no one can see me. Just because it is a private place does not mean I have to masturbate every time I am there.

Some children with ASD may misinterpret this to mean they must always need to masturbate when in a private room and may need clarification should this occur.

PLACES THAT ARE OKAY TO MASTURBATE:

- In my room with the doors and blinds closed so no one can see me
- On the toilet with the door closed
- In the shower with the door closed
- In the bath with the door closed
- In the shopping centre toilet with the cubical door closed
- If you feel that there are other places that would be more appropriate for your child to masturbate, you may add these to the list above. Although it may not be ideal for children to masturbate in a public toilet cubical, it should be noted that some children with ASD find that sexual release calms them and without such release their behaviour may deteriorate.

PLACES THAT ARE **NOT** OKAY TO MASTURBATE:

- Places with people around
- Other rooms in the house that are not my bedroom or the bathroom.
- In class
- In shops
- At friends houses
- In the car
- At the park
- Please amend the list to suit you and your child's needs.

Masturbation in public is not something all children with ASD will do, therefore it may not be appropriate to discuss this with your child.

Circle of Friends Activity

Self: This is me.

Family: These are the people who live at home with me.

Extended family: These are the people who are my family but don't live in my home with me. For example; my grandmother, my grandfather, my aunty, my uncle and my cousins.

Friends: A friend is different to an acquaintance. A friend is someone I know very well. My friends care about me and I care about them too. I trust my friends and they trust me.

Acquaintances: There is a difference between being an acquaintance and a friend. An acquaintance is someone whose name I know, who I see every now and then, whom I might have something in common with and who I feel comfortable around. For example; I might see this person only on the train and not in my home.

Teachers: These are the people who stand in front of the class at school and teach me things.

Helpers: These are the people who help with things that I find difficult.

Servers: These are the people who work in shops like cafes, restaurants or clothing stores. It is their job to serve customers like me

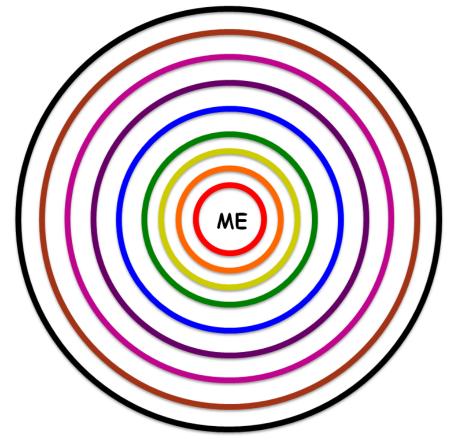
Strangers: A stranger is someone I do not know, I do not know their name and I have never seen them before.

INSTRUCTIONS:

* Discuss with your child who falls into each circle

* Discuss what level of touching contact should occur with each individual

* This activity will help highlight to your child which people are appropriate to touch and which are not.



EMOTIONAL CHANGES-INFORMATION FOR PARENTS

The transitions and changes of adolescence can be a difficult time for all adolescents, and can be especially difficult for children with an ASD for a number of reasons. A number of changes will take place; in addition to the physical and social changes previously discussed in the Physical and Social sections of this resource, adolescence is a time of emotional change.

Adolescence can involve changes to a person's perception of themself, their values, goals, and self-identity. It can involve changes in mood resulting from the physical changes to the body and its hormone levels (Plotnik & Kouyoumdjian, 2008). Difficulty understanding the emotions of others, difficultv controlling their own emotions. as well as depression (characterised by depressed mood and marked diminished interest or pleasure in almost all activities), anxiety (characterised by fear or worry related particular stimuli to or situations), anger, aggression, and difficulty forming self-identity (the way we view our own personality traits, morals and goals) and self-esteem (a sense of self-worth and confidence in communicating and understanding the information presented, it may be even more difficult to totally prepare them for the physical, social, and emotional changes they are about to experience. However, there are a number of strategies that can be used, outlined in this section, to ensure that the individual is as prepared as possible for the emotional changes they may soon be experiencing.

our own abilities), can emerge or be worsened by puberty in individuals with an ASD (Diagnostic and statistical manual of mental disorders, Forth edition – Text Revision (DSM-IV-TR) American Psychiatric Association (APA), 2000; Branden, 1992; Harre & Moghaddam, 2003; Volkmar & Wiesner, 2009).

Thus, in order to relieve the pressure and stresses of understanding the changes that are taking place it is essential to explain the processes that are occurring during this time.

The material within this information booklet is designed to assist you and your child with...

- 1. Understanding and managing the mood changes that may occur during this time
- 2. Understanding the emotions of others
- 3. Understanding and managing anxiety
- 4. Managing problematic behaviours
- 5. Understanding and developing selfidentity and self-esteem

It is not always possible to completely prepare adolescents with an ASD for the changes associated with puberty, as they may have difficulty communicating and understanding the information presented.

Note: As there is a wide range of intellectual and

communication levels between ASD. individuals with an the information and strategies suggested within this resource will need to be customised to ensure that they can be easily understood by the individual. For example, the vocabulary chosen, and the length of information contained in tailored tales or visual aids

(e.g. charts, schedules) can be altered depending on the level that the individual's parent or guardian feels will be the most appropriate.

MOOD CHANGES

There are a number of disorders that involve a disruption of mood, or the "pervasive and sustained emotion that colours the perception of the world" (DSM–IV–TR; APA, 2000, p. 825). These mood disorders include:

- Major Depressive Disorder: one or more Major Depressive Episodes (at least two weeks of depressed mood or loss of interest accompanied by at least four additional symptoms of depression – see Symptoms of depression in neurotypical individuals for more information).
- Dysthymic Disorder: at least two years of depressed mood for more days than not, accompanied by additional depressive symptoms that do not meet criteria for a Major Depressive Episode.
- Depressive Disorder Not Otherwise Specified: depressive symptoms that do not meet criteria for Major Depressive Disorder, Dysthymic Disorder or other psychological disorders.
- Bipolar I Disorder: one or more Manic Episodes (distinct periods in which there is an abnormally persistently or elevated, expansive, or irritable mood) or Mixed Episodes (period of time in which the criteria are met for both a Manic Episode and а Maior Depressive Episode).

- Bipolar II Disorder: one or more Major Depressive Episode accompanied by at least one Hypomanic Episode (elevated or irritable mood over the course of at least four days that does not meet criteria for Manic Episode).
- Cyclothymic Disorder: at least two years of periods of Hypomanic symptoms that do not meet criteria for a Manic Episode and numerous periods of depressive symptoms that do not meet criteria for a Major Depressive Episode.
- Bipolar Disorder Not Otherwise Specified: bipolar symptoms that do not meet criteria for any of the specific Bipolar Disorders.
- Disorder Due To Mood а General Medical Condition: prominent and persistent disturbance in mood that is judged to be a physiological consequence of а general medical condition.
- Substance-Induced Mood Disorder: prominent and persistent disturbance in mood that is judged to be a physiological consequence of a drug of abuse, a medication, or exposure to toxins.
- Mood Disorder Not Otherwise Specified: mood symptoms which do not meet criteria for a specific Mood Disorder.

Individuals with an ASD may experience rapid mood changes (or "mood swings") during adolescence, which can be more severe or frequent than their neurotypical peers (Volkmar & Wiesner, 2009).

- In individuals with ASD and a • comorbid intellectual disability difficulty communicating, or changes in mood can commonly take the form of irritability, tantrums, selfor injury (Volkmar & Wiesner, 2009).
- In individuals at the higherfunctioning end of the autism spectrum, mood changes are often demonstrated through difficulty adapting to change, trouble concentrating, or depression (Volkmar & Wiesner, 2009).

Although these mood changes can often resemble those associated with bipolar disorder (periods of hyperactivity alternating with periods of decreased activity or depression), it has not been proven that individuals with an ASD are more likely to experience bipolar disorder (Tilton, 2004; Volkmar & Wiesner, 2009).

Mood changes in adolescents with ASD can cause (or worsen) problematic behaviours such as temper tantrums and aggressive behaviours may behaviour. These individual's social interrupt the relationships, academic participation, be harmful and can even to themselves and others around them (Volkmar & Wiesner, 2009).

Specific examples of problematic behaviours and strategies to help manage these problematic behaviours will be discussed later on in this section.

Many of the problems caused by these mood changes stem from difficulties with awareness and regulation of emotions (Geller, 2005).

Emotional awareness and regulation:

Emotional awareness refers to our ability to identify which emotion we are feeling and the reason for it: emotional regulation refers to the ability to manage and control our emotions, as well as our ability to express them 2005: Matson & Sturmey, (Geller, 2011). Emotional regulation can include maintaining а particular emotion, increasing or decreasing the extent to which we feel an emotion, or changing an unwanted emotion into a different Regulating one. your emotions can take place while you are feeling that emotion, or before you begin to feel it (Geller, 2005).

Individuals with an ASD often have difficulty regulating their emotions (Matson & Sturmey, 2011). The reasons include:

- Having difficulty or requiring • more time to process information; this includes information about what is happening around them and how it makes them feel.
- Finding it difficult to associate emotions with their causes, or understand that an emotion is the result of something that happens to them.

- Having difficulty telling different emotions apart. For example, they may see all negative or unpleasant emotions as fear.
- Having difficulty choosing appropriate facial expressions, or knowing when to use them, to express their emotions to others.

Due to above mentioned the difficulties, an individual with an ASD may require help to understand and practice the skills involved in emotional regulation. To be able to use strategies to regulate or improve their mood, an individual must first be able to recognise the emotion that they are feeling, and determine (if possible) what caused this emotion. Some with adolescents autism will understand this concept already, some will learn to identify emotions quickly, and some will require help to practice this skill before they are able to use strategies to regulate their emotions independently (Geller, 2005).

Strategies for helping your child to determine between emotions

- Use tailored tales to illustrate situations or events that can cause a particular emotion. For example, to illustrate happiness, create a social story beina about happy: *"When* something good happens to me, I feel happy. Some things that make me happy are (enter child's favourite interests/hobbies/ activities/friends). When I feel happy, I smile and laugh."
- Use situations that arise as opportunities to discuss emotions.

For example, if the individual appears to be happy, discuss the emotion of happiness as the way you feel when something good happens or when you feel good inside; discuss that it often makes you smile or laugh; discuss the reason that you think that they are happy (i.e. if they are smiling, laughing, or doing something that they enjoy).

- Begin by practicing identifying more common emotions, such as happiness, anger, fear, surprise and tiredness. When the individual is able to reliably identify these emotions, progress to more complicated emotions such as excitement, jealousy, trust, disappointment, love, embarrassment, and sympathy.
- There are a number of children's books available that encourage children to identify their own emotions and provide strategies them manage to help their for emotions appropriately; example: Shy Spaghetti and Excited Eggs: A Kid's Menu of Feelings (Nemiroff & Annunziata, 2011) and My Roller Coaster Feelings Workbook (Herbert, Herbert & Herbert, 2008).

Increasing an individual with an ASD's awareness of their emotions has been shown to help them change and regulate these emotions (Matson & Sturmey, 2011).

Not all individuals with an ASD will learn to how identify their own emotions independently; however, if the individual learns to reliably identify the emotion that they are feeling, they can then begin to learn strategies to help them manage these emotions appropriately and identify when they need to ask for help or support, thus reducing behaviours that will disturb or harm themselves or others.

REGULATING MOOD

There are a number of strategies that an individual can use to help regulate emotions and control mood. These strategies (listed below) can be made into a list of steps for them to follow when they appear to be acting out of anger, frustration, sadness or fear. Remind the individual to follow the steps (by reading the steps and presenting visual reminders such as pictures of each step), and reinforce behaviour with praise and/or rewards when the steps are followed.



Strategies for helping your child to regulate their mood

- When the individual gets angry or frightened, encourage them to stop what they are doing and take a deep breath. They should continue to breathe at a slow, steady rate. *Explain that this will help their body calm down.*
- Simple muscle relaxation exercises, such as progressively tensing and relaxing each muscle group in the body (Press & Osterkamp, 2006) can also help them calm down. Explain that "doing these exercises will calm your body down - this will then help your brain calm down and you will feel better".
- Encourage the individual to walk away from the object or situation that is distressing them, or find a quiet place to sit for a little while – this will allow them to escape excessive sensory information

(e.g. too much noise, movement, language, etc) and the pressure of social interaction, which may cause or worsen their distress.

- Doing something they enjoy, such as reading their favourite book, playing on the computer or taking a walk outside may improve their mood. Make a visual list with pictures of the activities your child enjoys – display this list somewhere so that the individual can refer to it when they need to.
- If these actions do not make them feel better. encourage the individual to tell а parent/guardian/adult is what upsetting them and why – Explain that the adult might be able to help them fix the problem and then they will feel better. (Geller, 2005).
- The Alert Program see below:

The Alert Program

This program was developed by Sherry Shellenberger and Mary Sue Williams to encourage emotional regulation in children with ASD ("Alert Program™ Founders". 2007, September/October). It involves providing the individual with feedback about their current level of energy, alertness, and ability to concentrate. This feedback can take the form of an analogy, such as referring to their energy levels as a car engine:

 Explain to the individual that their body is like a car engine – sometimes it runs slowly and doesn't want to get going, sometimes it runs too quickly, and sometimes it runs just at the right speed.

- Say: "Your engine seems to be in low gear today – I can tell because it looks like hard work for you to get going", or "Your engine seems to be in a really high gear today – you're talking really fast and it looks like it's making it a bit hard for you to concentrate", or "Your engine seems to be running just right at moment the _ you can concentrate properly on what you're doing").
- The language and concepts involved in this analogy may be complicated too for the individual, or may not interest them. If the individual has a particular interest that you can use to represent their levels of energy and alertness, or if they already refer to their energy levels in a particular way, you may be able to use this language instead of the engine analogy.

Once they become familiar with the concept of their energy levels changing throughout an activity, establish a visual list of strategies that will help the individual either increase decrease their energy levels or (Williams & Shellenberger, 2006). strategies will differ from These individual to individual; however, here are some examples:

- To increase energy levels: jump up and down ten times, do ten push-ups, or walk around the room.
- To decrease energy levels: read a favourite book, sit and listen to music, or sit and take 10 deep, slow breaths.

When encouraged to use the strategies identified, many individuals will become better able to achieve an

ideal level of alertness and energy (either with prompting or independently), and may learn to independently identify when their energy levels are either too low or too high to allow them to function as effectively they can ("Alert as Program™ Founders", 2007. September/October).

Although the concepts may be too complex for some adolescents with an ASD, this program may still be useful in allowing adults or peers (including parents, teachers, friends, or other students at school) to communicate about the individual's energy levels ("Alert Program[™] Founders", 2007, September/October).

More information about this program can be found at The Alert Program website (<u>www.alertprogram.com</u>).

Understanding the emotions and perspectives of others

As well as experiencing difficulty with the process of identifying and interpreting their own emotions, people with an ASD may have difficulty picturing things from someone else's point of view, and understanding the thoughts and feelings of others; this ability is referred to as Theory of Mind (Bernier & Gerdts, 2010; Goldstein, Naglieri & Ozonoff, 2009).

However, keep in mind that some individuals ASD with are assumed to have significantly reduced Theory of Mind, when in fact their difficulty in social situations is not caused by an inability to recognise or another understand person's emotions, but by other factors; these include mav sensorv overload and withdrawal caused by their empathetic reaction to the other person's emotions, or an inability to understand the other person's social signals (such as facial expression, body language, tone of voice, topic maintenance, eye contact) and respond in a socially acceptable way (Serhan, 2011).

Difficulties with empathy and understanding different perspectives can lead to problems with social interaction and the formation of interpersonal relationships (Goldstein et al., 2009). There are several strategies that parents, guardians and caregivers can use to encourage the development of empathy.

> Strategies for increasing empathy and understanding of other people's perspectives

- The strategies outlined in Strategies for helping your child to determine between emotions are also useful in helping individuals with an ASD understand the emotions of others.
- tailored Develop tales about deliberately thinking about things from someone else's perspective. For example, create a social story about a class trip to the museum: "My friend Sarah really wanted to go to the museum. Sarah could not go to the museum. That made Sarah upset. don't like 1 museums. I like going to the football. I get upset when I cannot go to the football. So Sarah and I both get upset. Sarah gets upset about not going to the museum the same as I get upset about not

going to the football. Now I understand why Sarah was upset."

Use everyday situations as an opportunity to encourage individual to see situations from another person's perspective. Throughout your day, tell the individual how you are feeling, and why you are feeling that way. After some time, you can start to ask them to describe how they think you might be feeling about certain events.

For example: "I dropped my piece of toast on the floor! How would it make you feel if that happened to you?"

DEPRESSION

Adolescents who are on the autism spectrum have been shown to have a depression greater risk of (for symptoms of depression, see below) than their neurotypical peers. Depression is more commonly diagnosed in individuals at the higher functioning end of the autism spectrum; however, this may be due to difficulty in detecting the and identifying the symptoms of depression in individuals at the lower-functioning end of the spectrum, especially in individuals who do not communicate verbally (Nichols, Moravcik & Pulver Tetenbaum, 2009; Volkmar, Paul, Klin & Cohen, 2005).

Depression in individuals on the autism spectrum is often due to the individual's recognition that they are "different" from their peers, or the increasing of academic pressure and academic expectations (Volkmar et al., 2005; Volkmar & Wiesner, 2009). The difficulties in understanding social rules and expectations that these individuals often experience (see the Social section of this resource) mean that, although they generally want to friends and make form social relationships, they may not know which behaviours are socially acceptable and which social behaviours will help them achieve these relationships. This may lead to social isolation, which can also cause or worsen depression (Volkmar et al., 2005).

However, there are signs for parents, guardians, caregivers and teachers to watch for, and actions that can be taken to treat and manage depression if it does occur.

Symptoms of depression in neurotypical individuals

To be diagnosed with a major depressive episode, an individual must display at least five of the following symptoms during the same two week period: these symptoms must represent a change from previous functioning, and at least one of the symptoms must either be (1)depressed mood or (2) loss of interest or pleasure (DSM–IV–TR; APA, 2000):

- Depressed mood, nearly every day during most of the day
- Marked diminished interest or pleasure in almost all activities
- Significant weight loss or weight gain, or a change in appetite
- Changes in sleep (either sleeping too much or too little)
- Visible changes in the speed of bodily movements and speech (either reduced speed of movements or excessively fast or agitated movements)
- Fatigue or loss of energy
- Feelings of worthlessness or inappropriate guilt
- Indecisiveness or difficulty concentrating

• Recurrent thoughts of death or self-harm

The symptoms of depression in individuals who are on the autism spectrum are essentially the same as those of their neurotypical peers. However, while some individuals will display similar behaviours to neurotypical individuals with depression, a depressed individual with an ASD may frequently behave differently than the typical quite perception of people with depression (Goldstein et al., 2009; Nichols et al., 2009).

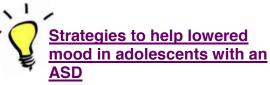
Possible behaviours that are reflective of symptoms of depression in individuals on the autism spectrum

- Increase in frequency or severity of repetitive or compulsive behaviours
- Onset or increase in temper tantrums or aggressive behaviour
- Onset or increase in irritability or agitation
- Onset or increase in selfinjurious behaviour or self-harm
- Decrease in everyday functioning across different situations or environments
- Preoccupation or obsession with death/dying
- Talking about suicide or harming themselves (Goldstein et al., 2009; Nichols et al., 2009; Volkmar et al., 2005)
- It is recommended that you take any comments about suicide or self-harm very seriously, and act immediately. Contact the individual's GP or the Intake Service for your local Child and Adolescent Mental Health Service

(refer to the **Useful contacts** section of this resource for contact information) immediately to discuss options for managing the individual's depression.

If the individual has not commented about self-harm or suicide, but does exhibit one or more of the above signs of depression, it is still important to contact the child's GP or a mental health professional as soon as possible.

If you have concerns regarding the individual's mood, there are several strategies that you can use, often in conjunction with the individual's teachers.



- Contact the individual's teacher(s) and ask them:
 - 1. Whether they have observed any of them symptoms or behaviours that you have observed at home.
 - 2. Whether they know of any reasons for the individual's apparent depression/change in mood (for example, whether they have many friends; how effectively they interact socially with their peers; whether they are being bullied; whether their schoolwork is too demanding or too much pressure).
- Contact your local Child and Adolescent Mental Health Services. The information obtained from the individual's teacher may be helpful in describing the individual's changes in mood to mental health

professionals at this service in order to facilitate a referral if appropriate.

- If either you or the individual's teacher have suggestions regarding the cause of the individual's symptoms, or factors that may be worsening their apparent depression, discuss ways to manage these factors with staff Child school and and Adolescent Mental Health Service professionals. For example:
- 1. Commencing social skills training/exercises can help the individual form social relationships.
- 2. Becoming socially involved in a hobby/area of interest can also help with the formation of social relationships.
- *3.* Having a mentor or tutor may assist your child in coping with the demands of their schoolwork.
- If the individual is being bullied, refer to **Self-Identity and Self-Esteem** later in this section of the resource for ways to manage this (Goldstein et al., 2009).

ANXIETY

There are a number of disorders that are categorised as Anxiety Disorders; these include Generalized anxiety disorder, Panic disorder (with or without agoraphobia), Agoraphobia without history of panic disorder, Specific phobia, Social phobia, Obsessive-compulsive disorder. Posttraumatic stress disorder, and Acute stress disorder (DSM-IV-TR; APA, 2000). The incidence of anxiety disorders in pre-school children is relatively the same in children on the autism spectrum as it is in their neurotypical peers. However, when children reach school age, and

especially adolescence, individuals on the autism spectrum have been shown to have a greater risk of anxiety disorders than their neurotypical peers (Goldstein et al., 2009; Nichols et al., 2009).

The most common anxiety disorders that occur in individuals with an ASD are:

- Specific Phobias: defined as a marked, persistent, and excessive or unreasonable fear of a specific object or situation (APA, 2000, p. 444).
- Examples of specific phobias can include fear of thunderstorms, dark places, or large crowds (Goldstein et al., 2009).

Adolescents with an ASD may also suffer from:

- Panic Disorder: • recurrent, unexpected "panic attacks" (a discrete period of intense fear or discomfort in the absence of real danger), followed by at least one month of persistent concern about having another panic attack, worry about the implications of the panic attack, significant behavioural or change related to the attacks (APA, 2000).
- Social Phobia: marked and persistent fear of social or performance situations in which embarrassment may occur (APA, 2000).
- Generalised Anxiety Disorder: at least six months of persistent and excessive anxiety and worry (APA, 2000; Goldstein et al., 2009; Nichols et al., 2009).

If you have observed symptoms of anxiety in an individual, there are several strategies that you can use to help minimise their anxiety.



Strategies for parents to decrease anxiety-provoking situations for individuals with an ASD

- Many individuals on the autism spectrum rely on routine and structure, and may become anxious or distressed if their routine is interrupted (Volkmar et al., 2005). Maintain a daily routine at home and school as much as possible.
- Displaying a visual timetable of daily activities (including: get up, have a shower, get dressed, have breakfast, brush teeth, etc) may help many individuals with an ASD keep track of what they need to be doing, and will reassure them as to what will be happening next (Barratt, Cassell & Hayes, 1998).
- When you need to change the individual's routine, discussing the new activity with them in advance is generally helpful. Small changes to the routine may be discussed with the individual the day or several days before. On the day, introduce the new activity or setting into the visual schedule for the day, to allow the individual to see how the activity fits in to the day's activities, and when the schedule will return to normal (Barratt et al., 1998).
- When discussing significant changes, such as moving house schools. changing or many individuals on the autism spectrum will benefit from being introduced to the idea of this change as early as possible (ie weeks or months earlier). However, for some individuals, beginning the preparations for the

change too far in advance will cause anxiety instead of relieving it (Wilkes, 2005). When deciding when to begin preparing the individual for the upcoming change, consider whether knowledge of upcoming changes has helped the individual accept changes to their routine in the past.

- As individuals on the autism spectrum may have difficulty understanding the socially acceptable ways of initiating, maintaining and ending а conversation, social interaction can cause significant anxiety (Volkmar et al., 2005). Providing particular place that the а adolescent can go to that is free from social or conversational interruption will help decrease or prevent this anxiety (Attwood, 1998; Volkmar et al., 2005).
- Engage the individual in an activity that requires physical exertion (*e.g. a trampoline or swing*) this can decrease anxiety and agitation (Attwood, 1998; Volkmar et al., 2005).
- At school discuss with teachers whether the individual can access somewhere quiet during times of anxiety or stress at break-time. Being able to spend some time without excessive sensory input or social interaction may prevent or help decrease anxiety in the schoolyard (Attwood, 1998; Volkmar et al., 2005).
- At school discuss with teachers if there is a way that the individual can have a short break from the classroom if required. For example: the teacher may be able to send them to the office or to

another teacher with a message if their anxiety levels appear to be rising. The individual and their teacher may even be able to develop a signal to allow the individual to signal that they are feeling anxious or overloaded with sensory information without attracting attention to themselves (Attwood, 1998; Volkmar et al., 2005).

Cognitive Behaviour Therapy (CBT) can also help to prevent or reduce anxiety in individuals on the autism spectrum (Attwood, 1998; Volkmar & Wiesner, 2009). This method of therapy is delivered by trained psychologists, and aims to change or restructure the way an individual thinks and the behaviours that occur as а reaction to the way they think. It can help increase reasoning skills the ability to interpret and situations appropriately, which decreases worrying, and behaviours caused by anxiety (including avoidance of certain situations. or an increase in repetitive behaviours) (Butler. Fennell & Hackmann, 2010). You can discuss whether or not CBT would be appropriate for the individual with their GP or paediatrician.

GIRLS- PMS AND EMOTIONAL CHANGES

Adolescent airls the autism on spectrum will still experience the same range of symptoms of PMS, including associated emotional symptoms (such as irritability, difficulty concentrating, depression, anxiety, withdrawal from social situations, difficulty sleeping, or excessive time spent sleeping) as their female neurotypical peers. However, if your daughter has difficulty communicating or with regulating her emotions, the emotional symptoms that she experiences may result in monthly incidences or increases in behavioural problems (Nichols et al., 2009).



Strategies for managing the emotional symptoms of PMS

- Explain to your daughter the range of symptoms that may be associated with PMS. Understanding why these symptoms are occurring and how long they are likely to last for will help increase your daughter's sense of stability and control over these changes to her body (Nichols et al., 2009).
- Use specific language and terminology and avoid colloquialisms when explaining these symptoms. For example, say "you might have a sore stomach" instead of "you might feel a bit funny in the tummy".
- Use tailored tales to illustrate the physical and emotional symptoms that your daughter appears to experience due to PMS. *For example, create a social story about getting your period: "For the*

first two weeks, Sarah feels fine. In the third week, she starts getting headaches, feels tired, and has trouble concentrating, and gets annoyed more often. She knows that this means she will probably get her period in a few days. She knows that these feelings will go away, and that she will soon feel better."

If you have started/plan to use the **Strategies for helping your child to regulate their mood** with your daughter, describe the girl using the strategies when she felt annoyed to make herself feel better.

• If your daughter's PMS symptoms seem to be severe or are preventing her from completing normal activities, contact her GP to discuss medical and other options for managing these symptoms (Nichols et al., 2009).

ANGER, AGGRESSION AND PROBLEMATIC BEHAVIOURS

The problems in social interaction and communication experienced by individuals on the autism spectrum frequently lead to expressions of feelings through behaviour. The expression of frustration, anger, or fear in individuals on the autism spectrum can often take the form of behaviours that are disruptive, aggressive and violent (Fouse & Wheeler, 1997).

In many cases, the individual is not wishing to disrupt or harm themselves or others, but simply to express their needs, wants, and feelings. For example, a temper tantrum may be the individual's way of expressing their frustration at not being able to communicate and make themselves understood (Fouse & Wheeler, 1997). Behavioural reactions to particular emotions can vary widely between individuals on the autism spectrum. For example:

- An individual on the highfunctioning end of the autism spectrum may display anxiety by fidgeting, nervousness, muscle tension, or excessive giggling (Fouse & Wheeler, 1997).
- An individual with a moderate intellectual disability on the autism spectrum may display their anxiety through increased movement and activity, excessive giggling or crying, or making strange or loud noises (Fouse & Wheeler, 1997).
- An individual with a severe • intellectual disability with an ASD may respond to their anxiety through temper tantrums, screaming, violent behaviour, or by withdrawing from the situation and "shutting down" (Fouse & Wheeler, 1997).

Factors that may cause/worsen aggressive or problematic behaviours

As a parent, guardian, or carer of individual on the autism spectrum, the task of determining the reason for the problematic behaviour or the message that the individual wishes to convey can be very difficult. However, there are a number of factors to consider when looking for the cause of the behaviour:

• <u>Sensory issues:</u> individuals on the autism spectrum may react differently to the sensations of touch, sight, hearing, smell and taste, and may have behavioural issues surrounding any of these senses (Fouse & Wheeler, 1997). For example, some individuals become defensive or aggressive with even a slight touch, or may have problems with touch on a particular area of the body (e.g. palms of the hands), or with particular textures. Some individuals prefer may increased levels of sensory information, and may require textured clothing or objects to them with provide sensory stimulation. Tantrums or behavioural problems may be individual's the way of expressing their dislike of a particular type of sensory information (Tilton, 2004).

- Social pressure and expectations: difficulty knowing which behaviours are socially acceptable, as well as those that are socially expected, can cause anxiety, as well as and frustration, agitation in individuals on the autism spectrum. These emotions can often translate into aggressive or violent behaviours (Fouse & Wheeler, 1997).
- Communication difficulties: similarly, difficulty understanding what is being said to them or difficultv expressing themselves can also cause distress and frustration in individuals (Fouse these & Wheeler, 1997). This often results in aggressive or violent behaviour, but alternatively may cause some individuals to withdraw from social situations (Tilton, 2004).
- <u>Deviation from routine and</u> <u>structure:</u> just as changes to routine can cause anxiety, they may also cause frustration, temper tantrums, or other

aggressive behaviours. Similarly, interrupting an individual's repetitive behaviour patterns can often cause frustration and aggression (Fouse & Wheeler, 1997).



Strategies for managing problematic behaviours

- lf the individual able is to communicate verbally, encourage them to tell you what is wrong so that you can understand why they are behaving in this way. Through their aggression, the individual may be trying to tell you they need or want something (Dodd, 2005). Although it is difficult do not get angry or yell. The individual should not feel like they are being punished for trying to communicate with you, but that there are nicer more efficient ways and to communicate their wants and needs.
- If the individual is not able or willing to stop and communicate with you about what is distressing them, the best thing to do during the tantrum itself is wait, and try to minimise the risk of harm to themselves or others (Fouse & Wheeler, 1997).
- Tailored tales (for example, the story about dealing with anger described in Strategies for individual helping the to determine between emotions) can encourage the individual to replace their problematic behaviours with a structured list of acceptable behaviours (Fouse & Wheeler, 1997).
- Visual schedules can also be useful in managing problematic behaviours. Create a list of tasks (for example, taking deep breaths,

asking an adult for help) with pictures for the individual to follow; explain that they should try to follow the list instead of reverting to temper tantrums or other problematic behavioural habits. When the problematic behaviour occurs, encourage them to follow the list, and reward them with praise and/or an activity they enjoy (Dodd, 2005).

Look for patterns: does the problematic behaviour always occur in the same situation, or every time they are exposed to a particular sight, sound, smell, taste, touch or texture? If you can identify a sensory issue that they have with a particular object or situation, you can then avoid or modify the objet or situation, and hopefully eliminate the problematic behaviour (Fouse & Wheeler, 1997).

Medications to manage problematic behaviours

At this point in time, no medications have been proven to treat or decrease the severity of the primary difficulties associated with an ASD (Volkmar & Weisner, 2009). However, there are currently a range of medications available that may be able to reduce or relieve of the symptoms some ASD associated with an (these including depression, symptoms hyperactivity, agitation, anxiety, aggression, obsessions and compulsions) (Volkmar & Wiesner, 2009).

It may be that your GP, Paediatrician, psychiatrist or psychologist can speak with you about the possibility of medication for the individual. Medication may be raised as being helpful in the following situations:

- If the individual experiences symptoms of ASD (these symptoms including depression, anxiety, hyperactivity, agitation, aggression, obsessions or compulsions) that are severe.
- If these symptoms interfere with the individual's participation in activities of daily living such as education, work, or community activities.

Your GP, paediatrician, or psychiatrist will be able to discuss with you the different medications available, their side effects, and whether the potential benefits would outweigh these side effects for the individual (Volkmar & Wiesner, 2009).

SELF-IDENTITY AND SELF-ESTEEM

In addition to the physical, social, and mood changes that are associated with adolescence, this transition from childhood adulthood to involves establishing your self-identity; that is, figuring out who you are and what your values are. It also involves building self-esteem; that is, viewing yourself as a valuable part of society, with individual values, skills and strengths. These issues that face all are adolescents, but people on the autism spectrum may have greater difficulty with self-identity and self-esteem than their neurotypical peers, for several reasons (Mesmere, 2007):

• They may have problems with emotional regulation, making it more difficult for them to determine how they feel about themselves, how they feel about certain issues, and what their values are surrounding these issues (Geller, 2005; Matson & Sturmey, 2011).

- They may experience difficulty with being different from their peers, and determining how they fit in with and relate to their peer group (Nichols et al., 2009).
- Depending on the level of care and support the individual needs from family and carers, they may find it difficult to understand, or may not be able to understand, the reasons that they are not likely to achieve total independence.

The development of their self-identity and self-esteem may be negatively influenced by bullying or by being treated differently by their peers, teachers, or others in the community (Serhan, 2011; Shore, Rastelli & Grandin, 2006).

It is important to discuss self-identity and self-esteem with the individual, and encourage them to share any questions or problems that they have. They may prefer to share this information and ask for advice from professionals or people that they do personally not know socially or (instead of coming to their parents, carers or teachers). Therefore, it may be helpful to let the individual know that there are other sources of information and advice, and provide them with a list of contacts. For example:

- counsellors
- The Autism Advisory and Support Service (AASS) 24 hour Australia-wide Autism hotline (more information is available from http://www.aass.org.au/)

 Online autism chat groups and discussion boards, such as the Autism Support Network (<u>http://www.autismsupportnetwo</u> <u>rk.com/</u>) or Healthful Chat Autism Chat Room (<u>http://www.healthfulchat.org/aut</u> <u>ism-chat-room.html</u>)



Strategies to encourage selfidentity and self-esteem

- Discuss with the individual the fact that everybody is different, and that is what makes us interesting as people. People can look different, speak differently, think differently or act differently to one another, and that is fine. Discuss the idea that, although they may feel different to the other children at school, or people might tell them that they're different, they are not the only ones who are different (Serhan, 2011).
- Convert the above discussion into a social story that you can read together.
- The individual may benefit from becoming involved with others with especially an ASD. other adolescents. This will allow them to gain a greater understanding of autism itself and the ways that it can affect different people, and to share their own experiences with an understanding audience. It will also provide them with opportunities to interact with others in a social environment (Volkmar et al., 2005).
- Encourage the individual to become socially involved in an activity that they enjoy (for example, joining a sporting club or a band) – this will help to give them a greater sense of who they are, what they enjoy and where they fit

in. It will also encourage the development of social skills, which is likely to help their self-esteem in the long run (Gabriels & Hill, 2008).

- the individual Encourage to their consider likes, dislikes, personality, and how they would describe themselves to others. One way to do this is to help them create an 'All About Me' book include pictures of things they like, pictures of friends, hobbies and You achievements. can also discuss words that they would use describe themselves. to and include these in the book (Nichols et al., 2009).
- There are also books available (including Can I Tell You about Asperger Syndrome?: A Guide for Friends and Family by Jude Welton and Jane Telford, and a number of other books available at Book In Hand: Autism and Asperger's Supplies http://www.bookinhand.com.au/ind ex.html), that discuss common characteristics and behaviours of individuals on the autism spectrum, and may help to prompt the
- It is important to understand that it may take individuals on the autism spectrum longer than their neurotypical peers to develop a true sense of who they are and what they are worth (Serhan, 2011).

individual to consider their own

personality traits and behaviours.

Emotional Changes

Bullying

Bullying involves being repeatedly exposed to negative actions on the part of one or more other individuals; this may include physical aggression (e.g. hitting, pinching, pulling hair, kicking, anything that involves hurting part of their body); verbal abuse (e.g. calling names, saying unkind or hurtful things); exclusion (e.g. avoiding talking to them, excluding them from group conversations or activities); indirect bullying (e.g. spreading rumours about someone to other people, or sharing someone's secrets with others); and cyberbullying (e.g. sending hurtful or offensive messages via text/email/social media) (Dodd, 2005). Bullying can significantly increase the risk of low self-esteem and depression (Sanders & Phye, 2004). If the bullying is persistent, it may affect social and emotional development, especially if it occurs during adolescence, which is an important time for developing these social and emotional skills. It can also impact on an individual's participation and performance in their classwork and school activities (Dodd, 2005).

Any child or adolescent can find themself the victim of bullying, whether they have an ASD or not. However, because individuals on the autism spectrum may have fewer friends, reduced social skills, difficulty understanding unspoken social cues (such as facial expression, bodv language) that provide information about how to respond appropriately in social situations, or have repetitive behaviours that appear different to their peers, they are a higher risk of being bullied than their neurotypical peers (Shore et al., 2006; Volkmar et al., 2005).

Strategies to manage bullying

Discuss with the individual what bullying is. Give specific examples of behaviours that are considered bullying, including: physical aggression (e.g. hitting, pinching, pulling hair, kicking, anything that involves hurting part of their body); verbal abuse (e.g. calling names, saving unkind or hurtful things); exclusion (e.g. avoiding talking to them, excluding them from group conversations or activities); indirect bullying (e.g. spreading rumours about someone to other people, or sharing someone's secrets with and cyberbullying (e.g. others); sending hurtful or offensive messages via text/email/social media) (Dodd, 2005).

- Ensure that the individual understands that all of the above behaviours are not acceptable, and that they should inform someone, ideally you or their teachers, if these behaviours occur, whether it is at school or outside of school (Dodd, 2005).
- Use tailored tales or a visual list of steps to encourage the individual not to retaliate against the bully, but to walk away from them (Dodd, 2005; Volkmar et al., 2005).

For example: "Sometimes people say mean things to other people, or laugh at them. People do it because they find it fun, or because they're bored. Nobody likes it when people say mean things to them. If someone says something mean to me, or laughs at me, I can say "I don't like that" or "I'm leaving", or I can just walk away from the person."

 Using these tailored tales as the basis for a role-play can be very valuable. Some individuals with an ASD will need to have their responses to the bully scripted, and some individuals will be able to move away from the scripted responses and adapt their responses to suit the specific situation being role-played (Dodd, 2005; Volkmar et al., 2005).

- If the bullying is occurring at school, discuss the individual's reports of bullying with your child's teacher(s). The teachers can then monitor the situation during class time to ensure that the bullying is prevented as much as possible, and also to ensure that the individual does not retaliate or respond aggressively to the bully (Dodd, 2005).
- It may also be helpful to discuss with school staff whether a "buddy system" or another form of peer support can be arranged, to ensure that the individual has someone looking out for them at break times/lunchtime, when a teacher may not be present (Dodd, 2005).

EMOTIONAL CHANGES-RESOURCES FOR ADOLECENTS

UNDERSTANDING OWN EMOTIONS

HAPPINESS

When something good happens to me, I feel happy. Some things that make me happy are.... When I feel happy I smile and laugh.



(enter child's favourite interests/hobbies/activities/friends).

SADNESS

When something bad happens to me, I feel sad. Some things that make me sad are... Sometimes I cry when I feel sad.

(enter things that have made the individual upset or sad in the past).

Adapt these stories to target the particular emotion or emotions that the individual has difficulty identifying, or create a series of tailored tales to increase the understanding of a range of emotions (such as anger, fear, surprise, tiredness, excitement, jealousy, trust, disappointment, love, embarrassment, and sympathy).

UNDERSTANDING THE EMOTIONS AND PERSPECTIVES OF OTHERS

My friend Sarah really wanted to go to the museum.

Sarah could not go to the museum.

That made Sarah upset.

I don't like museums.

I like going to the football.

I get upset when I cannot go to the football.

So Sarah and I both get upset.

Sarah gets upset about not going to the museum the same as I get upset about not going to the football.

Now I understand why Sarah was upset.

Adapt this story to refer to an actual event or situation which the individual had difficulty viewing from another person's perspective.

MANAGING BEHAVIOUR GETTING ANGRY

Sometimes things happen that make me feel angry.

Everyone gets angry at one time or another.

When I feel angry, I should stop what I am doing.



I should take a big breath in.



123 45 I should count to ten very slowly.

This will help me calm down and feel better ("Tailored tales", 2005).

Visual schedule: WHEN YOU GET ANGRY OR FRIGHTENED



Stop what you are doing

 Take big, slow breaths in and out

Walk away or find a quiet place to sit down



Do something you enjoy (insert a list of the child's favourite activities, with pictures)

This will help your body calm down (Geller, 2005).

Visual schedule: WHEN YOU FEEL WORRIED OR NERVOUS

Sit down somewhere • comfortable and quiet (like on your bed in your bedroom, or on a chair in an empty classroom make sure you ask your teacher first)

- Squeeze the muscles in your hands for 5 seconds, then relax them
- Squeeze the muscles in your arms for 5 seconds, then relax them
- Raise your eyebrows for 5 seconds, then relax them
- Squeeze your eyes shut for 5 seconds, then open them
- Open your mouth as wide as it will go for 5 seconds, then relax it
- Raise your shoulders up towards your ears for 5 seconds, then relax them
- Push your chest out and your shoulders back for 5 seconds, then relax
- Squeeze the muscles in your thighs for 5 seconds, then relax them
- Squeeze the muscles in your lower legs for 5 seconds, then relax them
- Squeeze the muscles in your feet for 5 seconds, then relax them

Doing these exercises will calm your body down - this will then help your brain calm down and help you feel better (Press & Osterkamp, 2006).

MANAGING PMS



For the first two weeks, I feel fine.

In the third week, I start getting headaches, and feel tired.

I have trouble concentrating, and get annoved more often.

I know that this means I will probably get my period in a few days.

I know that these feelings will go away, and that I will soon feel better.

Adapt this story to include the symptoms of PMS that the individual generally experiences.

this is what makes me an interesting person (Serhan, 2011).

MANAGING BULLYING

Brad told Daniel that he was fat and laughed. Daniel felt sad. Sometimes people say mean things to other people, or laugh at them. People do it because they find it fun, or because they're bored. Brad laughed because it was funny to him. Daniel was sad because it was not funny to him.



Nobody likes it when people say mean things to them. If someone says something mean to me, or laughs at me, I can say "I don't like that" or "I'm leaving", or I can just walk away from the person.

INCREASING SELF-IDENTITY AND SELF-ESTEEM

Everybody is different. That is what makes us interesting as people.



People can look different, speak differently, think differently or act differently to one another, and that is fine.



If we all looked, spoke, thought and acted the same, the world would be very boring!

I must remember that even if I feel different to the other children at school,

USEFUL CONTACTS

Child and Youth Mental Health Service/Child and Adolescent Mental Health Services (Victoria): http://www.health.vic.gov.au/mentalhe alth/services/child/index.htm For general enquiries or complaints: phone 1300 767 299 Postal address: Mental Health, Drugs & Regions Department of Health GPO Box 4057 MELBOURNE VIC 3001

Autism Advisory and Support Service (AASS) 24 hour Australiawide Autism hotline: 1300 222 777. For more information, visit http://www.aass.org.au/

Autism Victoria: http://www.autismvictoria.org.au/home/

Autism Support Network: http://www.autismsupportnetwork.com/

Healthful Chat Autism Chat Room:

http://www.healthfulchat.org/autismchat-room.html

Beyond Blue:

http://www.beyondblue.org.au/index.as px

Lifeline: http://www.lifeline.org.au/

Book In Hand: Autism and Asperger's Supplies: http://www.bookinhand.com.au/index.h tml

REFERENCES

American Autism Society. (2011). *Educating your child with autism about personal hygiene.* Retrieved October 10, 2011, from <u>http://www.americanautismsociety.org/</u> <u>educating-your-child-with-autism-</u> about-personal-hygiene/

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4th ed., text rev.).* Washington, DC: Author.

Attwood, T. (1998). Asperger's syndrome: A guide for parents and professionals. Philadelphia: Jessica Kingsley Publishers.

Attwood, T, (2009). Romantic relationships for young adults with Asperger's syndrome and highfunctioning autism. Retrieved October 10, 2011, from http://www.iancommunity.org/cs/article s/relationships.

Autism Victoria (2011). *Puberty and autism spectrum disorders.* Retrieved August 26, 2011, from <u>http://www.amaze.org.au/uploads/201</u>

<u>1/08/Fact-Sheet-Puberty-and-Autism-</u> <u>Spectrum-Disorders-Aug-2011.pdf</u>

Barratt, P., Cassell, C. & Hayes, B. (1998). *Autism: How to help your young child.* London: The National Autistic Society.

Bernier, R. & Gerdts, J. (2010). *Autism spectrum disorders: A reference handbook.* Santa Barbara: ABC-CLIO.

Better Health Channel. (2011). *Masturbation.* Retrieved October 10, 2011, from <u>http://www.betterhealth.vic.gov.au/bhc</u> v2/bhcarticles.nsf/pages/masturbation ?open Better Health Channel. (2011). *Puberty.* Retrieved August 26, 2011, from

http://www2.betterhealth.vic.gov.au/bh csearch/bhcsearch?start=0&searchtext =period&SearchTop=Search

Betts, D.E & Patrick, N.J., (2008). *Hints and tips for helping children with autism spectrum disorder.* London: Jessica Kingsley Publishers.

Butler, G., Fennell, M. & Hackmann, A. (2010). *Cognitive-behavioral therapy for anxiety disorders: Mastering clinical challenges.* New York: The Guilford Press.

Byrne, J. (2011). How to talk to your child about erections. *Live strong database.* [Online]. Retrieved October 1, 2011, from http://www.livestrong.com/article/1871 09-how-to-talk-to-a-child-about-erections/

Council for Exceptional Children. (2011). *Autism.* Retrieved August 26, 2011, from <u>http://www.cec.sped.org/AM/Template.</u> <u>cfm?Section=Autism_Asperger_s_Syn</u> <u>drome&Template=/TaggedPage/Tagg</u> <u>edPageDisplay.cfm&TPLID=37&Conte</u> <u>ntID=5598</u>

Dodd, S. (2005). *Understanding autism*. Marrickville: Elsevier Australia.

Dunlap, G. & Fox, L. (2006). *Teaching* students with autism. Retrieved August 26, 2011, from http://www.kidneeds.com/diagnostic_c ategories/articles/teach_students_autis m.htm

Farex. (2011). *Stalking.* Retrieved August 26, 2011, from <u>http://legal-</u> <u>dictionary.thefreedictionary.com/Stalki</u> <u>ng</u> Fouse, B. & Wheeler, M. (1997). *A treasure chest of behavioral strategies for individuals with autism.* Texas: Future Horizons.

Gabriels, R. L. & Hill, D. E. (2008). *Autism: From research to individualized practice.* London: Jessica Kingsley Publishers.

Geller. (2005). *Autism spectrum quarterly.* Retrieved 26 August, 2011, from <u>http://www.aspfi.org/documents/gellera</u>

<u>sq.pdf</u>

Goldstein, S., Naglieri, J. A. & Ozonoff, S. (2009). *Assessment of autism spectrum disorders.* New York: The Guilford Press.

Goulstein, M. (2010). *Good touch, bad touch, no touch.* Retrieved August 25, from

http://www.psychologytoday.com/blog/j ust-listen/201003/good-touch-badtouch-no-touch

Haywood, B. & Saunders, K. (2010). Sexual behaviours of concern in young people with autism spectrum disorders. In 10th Annual DSW Conference, Melbourne. Melbourne: Australasian Society for Intellectual Disability. Retrieved from http://www.asid.asn.au/Portals/0/Confe rences/DSW10/DSW10ConfPapers/Ha yward SexualBehaviours.pdf

Hoehn, K., & Marieb, E. (2007). *Human anatomy & physiology (7th ed.).* San Francisco: Pearson Benjamin Cummings Publishing.

Kids Health. (2011). *Puberty and periods.* Retrieved October 7, 2011, from <u>http://kidshealth.org/teen/sexual_healt</u> <u>h/girls/menstruation.html</u>

Legal Aid Queensland. (1997). *Stalking.* Retrieved August 26, 2011, from

http://www.legalaid.qld.gov.au/legalinfo rmation/thejusticesystem/Offences/Pa ges/Stalking.aspx

Matson, J. L. & Sturmey, P. (2011). International handbook of autism and pervasive developmental disorders. New York: Springer.

Meet the Alert Program[™] founders (2007, September/October). Autism-Asperger's Digest Magazine, pp. 42-43. Retrieved from <u>http://www.alertprogram.com/documen</u> <u>ts/Autism-Aspergers-Article.pdf</u>)

Mesmere, B. S. (2007). *New autism research developments.* New York: Nova Science Publishers, Inc.

Morris, B.K. (2008). *Support for parents dealing with ASD.* Retrieved October 10, 2011, from <u>www.autism-help.org</u>

Nichols, S., Moravcik, G. M. & Pulver Tetenbaum, S. (2009). *Girls growing up on the autism spectrum: What parents and professionals should know about the pre-teen and teenage years.* Philadelphia: Jessica Kingsley Publishers.

Plotnik, R. & Kouyoumdjian, H. (2008). *Introduction to psychology (8th ed.).* California: Thomson Learning, Inc.

Press, A. N & Osterkamp, L. (2006). *Stress? Find your balance (4th ed.).* Colorado: Preventative Measures, Inc.

Saltz, G. (2006). *Amazing you; Getting smart about your private parts.* North Carolina: Baker & Taylor.

Schaefer, V. (1998). *The care and keeping of you; The body book for girls.* Wisconsin: American Girl Publishing.

Serhan, R. J. (2011). *Psyche-smart autism*. Albuquerque: Sovereign Autism Research.

Shore, S. M., Rastelli, L. G. & Grandin, T. (2006). *Understanding autism for dummies.* New Jersey: Wiley Publishing, Inc.

Teens Health. (2011). *What is autism?* Retrieved August 25, 2011, from <u>http://kidshealth.org/teen/diseases_co</u><u>nditions/learning/autism.html</u>

The Children's Hospital of Philadelphia. (2005). *Sample stories*. Retrieved July 29, 2011, from <u>http://www.raisingdeafkids.org/growing</u> <u>up/toddler/tantrums/story.jsp</u>

Tilton, A. J. (2004). *The everything parent's guide to children with autism: Know what to expect, find the help you need, and get through the day.* Massachusetts: F + W Publications, Inc.

Volkmar, F. R., Paul, R., Klin, A. & Cohen, D. J. (2005). *Handbook of autism and pervasive developmental disorders: Assessment, intervention,*

and policy (3rd ed.). New Jersey: John Wiley & Sons, Inc.

Volkmar, F. R., Wiesner, L. A. (2009). A practical guide to autism: What every parent, family member, and teacher needs to know. New Jersey: John Wiley and Sons.

WHO. (2011). *Child and adolescent health and development*. Retrieved September 28, 2011, from <u>http://www.who.int/child_adolescent_h</u> <u>ealth/topics/development/en/</u>

Wilkes, K. (2005). *Moving house: A guide for children with autistic spectrum disorders.* London: National Autistic Society.

Williams, M. S. & Shellenberger, S. (2006). *Test Drive: Introducing the Alert Program through song*. New Mexico: TherapyWorks, Inc.

Workforce Council. (2011). *Autism - Decreasing unwanted behaviours – Masturbation*. Retrieved September 28, 2011, from <u>http://www.noahsark.net.au/PDF/Autism sexual behaviour guidance.pdf</u>

Wrobel, M. (2003). Taking care of myself; A hygiene, puberty and personal curriculum for young people with autism. Texas: Future horizons.



Faculty of Health Sciences La Trobe University Victoria, Australia 3086 T+61 3 9479 0000 F+61 3 9479 0000 Exxx@latrobe.edu.au

www.latrobe.edu.au/xxx

Disclaimer: The information contained in this brochure is indicative only and is designed as an aid to students contemplating enrolment. While every effort is made to provide full and accurate information at the time of publication, the University does not give any warranties in relation to the accuracy and completeness of the contents. The University does not accept responsibility for any loss or damage occasioned by use of the information contained in this publication. The University also reserves the right to discontinue or vary arrangements, courses, subjects (units), assessment requirements and admission requirements. While the University will try to avoid or minimise any inconvenience, changes may also be made to courses, subjects (units), assessment requirements and staff after enrolment. The University may also set limits on the number of students in a course or subject (unit). For course information updates, please??visit????wwwlatrobeeduaucoursefinder