

Learning Resource on Autism Spectrum Disorders (ASDs) For GPs & Primary Care Practitioners



<http://www.nes.scot.nhs.uk/asd/index.htm>

Topic One : The Patient with an ASD

A: How an ASD might impact on the individual

B: Sensory differences and how they can impact on behaviour

C: Understanding the meaning of behaviour

This Resource is designed for any professional who is working in the health care system at the primary care level (eg General Practitioner); Allied Health Professionals (eg dietitians, occupational therapists, physiotherapists, podiatrists and speech and language therapists); Dentists, Opticians, Public Health Nurses; District Nurses; Practice Nurses; and Dental nurses).

A: How an ASD might impact on the individual

A heterogeneous disorder

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The person with an Autism Spectrum Disorder (ASD) will have major impairments in three areas of development and will show a different developmental profile from the general population. Nevertheless, there are no 'typical' cases in this field.

People with ASD are individuals. Differences rather than similarities prevail in spite of a common triad. Some impairments can be quite subtle.

'People with autism come in as many shapes and sizes as 'people with pneumonia'. They have different races, social circumstances, intellectual levels, personalities and associated disorders. They should not be expected to conform to a highly specific prototype or to benefit from exactly the same kind of intervention, treatment or training. First and foremost they are people. It so happens that they are affected by the same (or similar) disorder but this does not make them blueprints of each other.' - (Peeters, & Gillberg, 1999) pp14-15

The Triad of Impairments

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The framework of the Triad of Impairments (Wing 1996) gives common areas of development that are affected in people with ASD and has facilitated the development of clearer diagnostic criteria.

This framework has also led to growing recognition of the different ways in which an ASD affects people at different levels of cognitive ability and at different ages and stages of development. It has helped establish the distinctive nature of ASD with respect to other conditions.

The Triad of Impairments:

Three major areas of developmental impairments need to be evident for a diagnosis of ASD to be made. The difficulties relate to :

- Communication
- Social and emotional understanding and social interaction
- Flexibility of thinking and behaviour

The Triad of Impairments

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Communication difficulties

Language difficulties are often associated with ASD but structural language problems are only apparent in those with classical autism; other individuals with ASD may develop spoken language at the usual age. The core difficulty lies in using language to communicate with others or understanding how others do so. It is the process of communication itself that is affected in individuals with ASD.

This can take the form of:

- No understanding of what communication is used for No apparent interest in communication
- Facial expressions and communicative gestures can be confusing for the individual to interpret
- Intonation can be heard but the individual has difficulty with understanding what the communication pattern conveys
- The individual has difficulty engaging in conversations and processing verbal information
- Language is interpreted literally and the individual finds it difficult to go beyond the words to understand what the speaker meant
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The Triad of Impairments

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Social Difficulties

People with ASD will have difficulty in understanding social signals or the social significance of behaviour. They will have difficulty in learning these intuitively and they are hard to teach formally as social rules change with context.

Difficulties with social interaction will depend on the age of the person, his/her developmental level and the severity of the disorder, but these difficulties continue into adulthood and throughout life although in some they become less obvious.

This can take the form of:

- Being socially withdrawn and isolated
- Having difficulty relating to adults or peers
- Dependency on familiar adults and siblings but difficulty initiating social contact with others
- Difficulty making and sustaining friendships
- Appearing very sociable and trying to dominate contact with others yet not being able to get that interaction right

- Appearing socially awkward and naive

The Triad of Impairments

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Flexibility in thinking and behaviour

Autism Spectrum Disorders are characterised by ritualistic behaviours, reliance on routines and extreme delay in, or absence of, social pretend play.

This can take the form of:

- Difficulty joining in with others in typical pretend play situations in childhood
- Difficulty generalising learning to new situations or problem- solving outside cued rote responses
- Difficulty broadening interests to other than a few, narrow, often obsessional or compulsive ones that dominate thinking and behaviour
- Difficulty in managing change to familiar routines (eg routes; layout; timetables)
- Difficulty inhibiting behaviour without an alternative.

The Infant Or Young Child With An ASD

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When an infant or young child presents for an appointment, a parent might report concern and worry in relation to a number of developmental issues. It is crucial to pay close attention to parents/carers' concerns about language, social skills and unusual behaviours.

Many studies document that parental concerns about developmental delays in their children are typically well founded. It is not helpful, and potentially harmful, to tell parents not to worry or to wait and see.

In an infant, observe:

- Mutuality of eye contact
- Social smile
- Joint attention
- Attention to activities in the room
- Interest in people versus interest in objects
- Babbling
- Interest in communication
- Facial expressions and gesture
- Variation of expressed emotion
- Crying and irritability without apparent motivation
- Reaction towards sound
- Body contact
- Rhythm and interaction
- Raising position when put on stomach
- Capacity for imitation
- Time span for reactions
- Responding capacities
- Sitting stability
- Body tone

- Eye-hand co-ordination
- Body rotation
- Keeping the head in bodyline when lifted
- Symmetric movements when crawling

The Infant Or Young Child With An ASD

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Close observation of the toddler or young child during the appointment, may point towards early signs of ASD. There are some key aspects to be alert for.

During the visit, look for:

- Does the child respond when you point to a toy and call the child's name?
- How does the child indicate what s/he needs?
- Does the child ask verbally?
- Does the child point or vocalise?
- Does the child point to call attention or use eye contact?
- Does the child show or share things with others?
- Does the child share in the activities of others?
- Does the child show any interest in what you are doing?
- Try to look beyond any difficult behaviour

The Infant Or Young Child With An ASD

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Communication

Although ASD is best characterised by impairments in social interaction, parents/carers more commonly express concerns with speech delay and difficult behaviours in young children.

There are some key developmental delays to be aware of in the initial stages of becoming concerned.

Listed are some key alerts in relation to **communication**.

Alerts for the practitioner:

- Language delay or abnormal language use
- Little attempt to communicate
- Showing little interest in the speech of others
- Language that consists mainly of immediate or delayed repetitions of what is heard
- Spontaneous communication that is stereotyped or unusual
- Loss of language or development that has slowed/stopped in relation to language skills (most commonly in the second year of life)

The Infant Or Young Child With An ASD

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Social interaction

Impaired social interaction and understanding in the young child may be subtle and may require specific questioning to elicit.

It should be noted that the fact that a child may give eye contact or affection does not exclude the diagnosis of an ASD. Many children with ASD do demonstrate affection and make eye contact, but on their terms.

Alerts for the practitioner:

- Limited use of non-verbal communication (eye contact, facial expression, body posture and gestures) in social situations
- Difficulty sharing enjoyment with others
- Lack of reciprocal interaction with others
- Ignoring other people or appearing relatively insensitive to their needs, thoughts or feelings.
- Difficulties in interacting with same-age peers and in forming friendships

The Infant Or Young Child With An ASD

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Flexibility of thinking and behaviour

Children with ASD show a tendency to routinised behaviour, resistance to change and sometimes have unusually intense interests.

Interrupting these activities and interests can lead to distress.

Behaviours that are not specific to ASD, such as extreme tantrums or self-injury, can therefore often be particularly problematic when children are young.

Alerts for the practitioner:

- Stereotyped routines of play
- Extreme food fads in relation to texture, taste and smell
- Lack of non-echoic imitation
- Insistence on specific non-functional routines or rituals
- Becoming upset by minor environmental changes
- Undue preoccupation with objects, (eg elements of play materials such as wheels or wrappings)
- Stereotyped and repetitive motor mannerisms, for example hand or finger flapping or twisting, or whole body movements

A Young Person With Asperger Syndrome

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Communication

A child, teenager or adult with Asperger syndrome (AS) can present in a very different way and with a different set of alerts.

A person with AS will lack any clinically significant general delay in language or cognitive development.

Yet there will be issues in relation to communication that can raise an alert.

Alerts for the practitioner:

- Formal and stereotypical language, including conversational difficulties

- Limited non-verbal communication to augment the verbal communication
- "To-and-fro" conversations are lacking- conversations are more like monologues
- Difficulty in using speech for communicate wishes or needs
- Limited or unusual use of non-verbal communication (eye contact, facial expression, body posture and gestures) in social situations
- Tendency towards literal interpretation of comments
- Over-precise or pedantic speech (often perfect English)

A Young Person With Asperger Syndrome

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Social interaction

The social difficulties of young people with Asperger syndrome (AS) are similar to other young people with ASD but often more subtle: they may miss the unspoken rules of social interaction and fail to 'read' social situations

Difficult issues are more likely to be focused upon social interaction and friendships. Many young people with AS will be having difficulties fitting in with the social context they are in and many young people with AS are bullied or rejected by peers.

Alerts for the practitioner:

- Deficient make-believe and social play
- The person has difficulty interacting with same-age peers and in forming friendships
- The person seems unaware of social conventions and codes of conduct
- Little evidence of empathy
- Difficulty in the expression of emotion and giving the 'wrong' emotion

A Young Person With Asperger Syndrome

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Flexibility of thinking and behaviour

The person with Asperger syndrome (AS) is likely to become fascinated by a special interest. This can take the form of collecting specific items or a fascination with a topic. It can exclude other activities, there can be repetitive adherence and the person's life may be dominated by this activity.

It may be that the interest appears, on the surface, to be appropriate for a person of that age. Individuals with AS often aspire to the usual markers of adolescent and adult status. It may be necessary to explore whether the interest is more intense or more rigid than would generally be expected.

Alerts for the practitioner

- Lack of social imagination
- Resistance to change and sometimes unusually intense interests
- Insistence on specific non-functional routines or rituals
- Upset by minor environmental changes in familiar situations
- Preoccupation with certain objects, activities or intellectual interests, which are sometimes unusual in quality or for their age (eg architectural terms; light fittings; paper)

An Adult With An ASD

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General

The description of the triad of impairments, as described above, also applies to the adult with an ASD, and as with the child and young person, the condition will be manifested differently in different individuals.

Awareness and identification of ASD in children has improved in the UK in recent years ([Wing & Potter, 2002](#)). However, the protocol for the diagnosis of adults tends to be less consistent and there may be an assumption that an individual will have been assessed at an earlier age. This is often not the case and a significant number of individuals will reach adulthood without having had a diagnostic assessment.

There are undiagnosed or misdiagnosed adults in all parts of the spectrum ([Howlin & Asgharian, 1999](#)). Undiagnosed adults are unlikely to have received appropriate support, either in their development or in their adult lives and they are very likely to have had their difficulties misinterpreted. They may well have developed additional problems as a result of previously having received the wrong type of treatment, or even punishment, for their behaviour. Often it will be these additional problems that bring them to the attention of the practitioner.

An Adult With An ASD

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Communication

The patients may appear at first to have good communication skills. However it may gradually become apparent that they do not understand everything said to them, or even everything that they themselves say.

Alternatively they may appear to have no communication at all and be taking no interest in the communication of others.

Often this is misleading and the individual will in fact have more understanding of the situation than is apparent.

Alerts for the practitioner:

An adult may present with one or more of:

- A history of having learnt and then lost communication skills
- A mismatch between expressive and receptive communication skills
- Seemingly no interest in communicating, except to express needs or demands
- Idiosyncratic communication style, often not reflecting age/cultural background
- Limited awareness of the reciprocal nature of communication.

An Adult With An ASD

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Social interaction

Some adults with ASD will seem oblivious to the social world and focused entirely on their own needs. Others will be socially aware and seemingly have social understanding.

Adults with ASD often develop competent communication skills over time, at least at a superficial level, and these skills can serve to mask the social problems they are experiencing.

However, the social world is such a complex one, and the requirement to 'fit in' so great, that a difficulty in this area may well provide the first clue that a patient has an ASD. Close, direct questioning will often reveal a history of social difficulties and rejection by peers.

Alerts for the practitioner:

An adult may present with one or more of:

- Appears to have more interest in objects than other people
- Socially uninhibited
- Interested in others seems limited to using them as either 'helper' or 'audience'
- Seems immature, looking and acting much younger than they actually are (even older adults)
- Is socially detached or isolated
- History of problems 'fitting in' and often has difficulty understanding why; feels they have been victimised
- Appearance and dress is not in keeping with their age, background or culture

An Adult With An ASD

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Flexibility of thinking and behaviour

Whatever the level of functioning, it is very common for adults with ASD to develop and depend on routines and rituals.

These serve to provide an element of predictability and control. Whilst the same is true of children with ASD, it is important to appreciate the different context that applies for adults.

Specialist support services for adults are still relatively rare in the UK, and adults with ASD may have had little or no appropriate input from professionals and/or carers. Without the right level and type of support, rigid patterns of thought and behaviour may have grown and developed over many years.

Non-routine appointments will inevitably cause disruption to routines that may be very important to the individual concerned.

In a clinical setting, therefore, rigidity of thinking and behaviour will often manifest itself as anxiety and distress at the unexpected change to routine caused by the appointment.

Alerts for the practitioner:

An adult may present with one or more of:

- A history of having interests and obsessions, often to the detriment of their own well being
- Fixed ideas and narrow interpretations
- Placing disproportionate importance on habits and routines
- Seeming to have difficulty resolving past problems and remaining traumatised by events from the past
- Being overly distressed and distracted by minor difficulties encountered en route or just prior to the appointment

An Adult With An ASD

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Flexibility of thinking and behaviour

When presented with a situation of concern, there are some key recommendations. These are listed below:

- Listen to the parents/ carers' concerns
- Observe behaviour carefully
- Refer on if there is definite delay or deviation outside the norm
- Provide ongoing support to families including referral to local and national parent organizations and agencies which provide respite

Sensory differences

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Sensory differences are often associated with ASD although these do not need to be present for a diagnosis to be made. The range of differences and the way they are experienced will vary from individual to individual.

There is no consensus about whether sensory differences arise directly from ASD or whether they are a secondary consequence of perceptual problems in categorising and making sense of the world around them. Whatever the case, personal accounts show that they are a dominant feature of the experience of those with ASD. Sensory differences are often more problematic when the environment is not adapted.

- Sensory difficulties are often 'invisible' or undetected in individuals with ASD
- People with ASD are very different in their sensory profile
- Treatment interventions that are appropriate for one person can be harmful to another
- It is not known whether these differences apply across the spectrum
- Little is known about the exact nature of these differences

Sensory differences

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People with ASD can either be hyper sensitive or hypo sensitive to stimuli in any of the sensory systems.

This can include experiencing both extremes in the same sense. A person with autism can therefore be hyper sensitive at one point in time and then hypo sensitive at another. [Bogdashina \(2003\)](#) describes this as inconsistency of perception.

- A person who appears to be hard of hearing on one occasion may react to an everyday sound on another occasion as if it is causing acute pain
- Visual stimuli that may appear painfully bright on one occasion will on another occasion appear very dim
- Reaction to pain may vary from almost complete insensitivity to apparent "over-reaction" to the slightest knock

Sensory differences

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Hyper sensitivities:

The person is very sensitive to certain sensory experiences. [Sainsbury \(2000\)](#) describes this as the volume of a particular sense being turned up too high.

Examples of Hyper sensitivities:

- Sensitivity to bright light or the flicker of fluorescent lights
- Being fascinated with light and reflection
- Intense perception of colours
- The smell or taste of any food is too strong
- Intolerance of the texture of certain foods
- Painful reaction to loud and / or high noises
- Overreaction to hot/cold
- Intolerance of the feel of clothes or shoes
- Extreme touch sensitivity

Sensory differences

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Hypo sensitivities:

The person does not react to stimulation as would be expected. There can, for example, be minimal reaction to pain and temperature. [Sainsbury \(2000\)](#) describes this as the volume of a particular sense being too low.

Examples of Hypo sensitivities

- Seems not to feel pain or temperature.
- Prone to inadvertent self-injury
- Seeks deep pressure (e.g. crawls under heavy carpets) and tight clothes
- Appears not to hear certain sounds
- The person might wave his/her hands around or rock back and forth or make strange noises in order to stimulate the senses

Sensory differences

(Page 6/24)

These sensory differences have led to many children and adults with ASD having been misdiagnosed as having visual and/or auditory impairments.

- Many children with ASD are suspected of being deaf, as they sometimes do not react appropriately to sounds or words.
- Despite this, hearing can be more acute than average, but the person might have learnt to 'switch off' when he/she experiences sensory overload
- When total sensory input becomes too intense and often painful a person learns to shut off sensory channels and can withdraw into his/her own world

Sensory differences

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Sensory differences can interfere with daily living in many people with ASD. It can range from the person not recognising a familiar environment if approached from a different direction *or* finding it difficult to do something in a noisy, crowded room. The person might find it very difficult to understand instructions if more than one person is talking.

Interference with daily living:

- The fear of noise may lead to a person becoming imprisoned in their own home rather than go out
- Sounds or visual stimuli can cause pain, confusion and fear, leading to the person being unable to cope in many situations, such as the classroom, visits to the supermarket or visits to the clinic
- Difficulty in 'backgrounding' and 'foregrounding' stimulation may mean that the person is distracted by 'irrelevant' noises / and visual details
- Many people with ASD are scared of the public address system, such as bells, fire alarms, or their name being called at the clinic, because the sound causes discomfort or pain
- Screeching electronic feedback from public address systems or the sound of fire alarms are particularly bad because they cannot be predicted and have a penetrating quality

Sensory differences

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Practitioners working with a person with ASD need to observe carefully to check for possible sensory difficulties. By looking at how the person reacts, it is possible to reconstruct and assess the person's differences in various sensory channels.

Signs of sensory differences:

- They put their hands over their ears (sensitivity to noise)
- They flick their fingers in front of their eyes (visual sensitivity)
- They have tantrums at the supermarket (sensory overload)
- They do not appear to hear certain sounds or show panic reactions to certain unexpected sounds (noise)

The Senses

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Vision

Vision can be very acute. This can include sensitivity to particular kinds of illumination and colours.

This can include

- Noticing the tiniest pieces of fluff on the carpet
- Avoiding bright lights and sunlight
- Looking down most of the time
- Being frightened by sharp flashes of light
- Visual distortion
- Attraction to lights
- Fascination with reflections and bright coloured objects

The Senses

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Vision

Some people with reduced visio spacial awareness on the other hand may experience trouble figuring out where objects are, as they just see outlines.

This can include

- Walking round objects running hands around the edges in order to recognise what it is
- If the person enters an unfamiliar room s/he may have to walk around it touching everything before settling down
- The person might sit for hours moving fingers or objects in front of the eyes.

The Senses

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Hearing

There can be sensitivity to different kinds of sounds. This can include noisy shopping centres and machinery in the distance.

In the clinic, this can include the sound of a busy waiting room and the sound of medical equipment or hand driers for example.

Individuals with **hyper accusis** often cover their ears when the noise is painful for them, though others in the same room may be unaware of any disturbing sounds at all.

- The person may describe their hearing as akin to having a sound amplifier on maximum loudness
- The person may be a very light sleeper
- Unpredictable sounds can be frightening (eg telephone ringing, baby crying, people coughing)
- The person seems unable to moderate incoming auditory stimulation
- The person seems unable to screen out sounds (eg speaking on the phone at a noisy airport)
- The person finds high pitched continuous noise annoying
- Sometimes hyper auditory people (as well as those with hypo accusis) make repetitive noises to block out disturbing sounds

The Senses

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Hearing

People with **hypo accusis** may 'seek sounds' They often create sounds themselves to stimulate their hearing. This can include banging doors, tapping things, tearing or crumpling paper and making loud rhythmic sounds.

This can include:

- Leaning their ear against electric equipment
- Enjoying crowds
- Enjoying loud sounds such as sirens

The Senses

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Tactile

There can be extreme sensitivity to a particular intensity of touch or touching of particular parts of the body. Clothing problems are very common in this group, with tags and scratchy materials being frequent offenders. Many people with ASD find labels in clothes very annoying. Many cannot tolerate zips or buttons on clothing. Small itches and scratches can feel like torture to some people.

Problems may arise in respect to:

- Touch used in social gatherings (e.g. handshakes) or even having to sit too close to others in the waiting room
- Dislike of the sensations of particular types of clothing (or aspects of clothing such as zips) on the body
- Strong interests in particular textures
- A need for 'deep' touch and seeking experiences to achieve this

The Senses

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Tactile

There can be sensitivity to the physical proximity to others and the perception of touch, pressure, pain and temperature can be intensified. Some individuals with ASDs pull away when people try to hug them, because they fear being touched. Because of their hyper tactility, even the slightest touch can send them into a panic attack. Parents often report that washing their child's hair or cutting nails turns into an ordeal demanding several people to complete it. Some people with increased tactile awareness overreact to heat/cold, avoid wearing shoes, avoid getting 'messy' and dislike foods of a certain texture.

Those with reduced tactile awareness seem not to feel pain or temperature. They may not notice a wound caused by a sharp object or they may seem unaware of a fractured bone. They are prone to self-injuries and may bite their hand or bang their head against the wall to stimulate their senses. They like deep pressure, including tight clothes, often crawling under heavy objects. They may hug tightly (although reject being hugged) and enjoy rough and tumble play.

"Being in close proximity to others is a particular problem for some people with Asperger's and deliberately arriving at lessons early in order to capture a seat on an aisle or in a corner was a common strategy." [Sainsbury \(2000\) p. 102](#)

The Senses

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Vestibular system

People with *vestibular hypersensitivity* or *hyposensitivity* often experience extreme differences in their reaction to their environment.

Vestibular *hyposensitivity*, can lead to:

- Seeking and enjoying all sorts of movement
- Being able to spin or swing for a long time without being dizzy or nauseated

- Enjoyment in rocking back and forth or move in circles while rocking their body
- Lying on ledges or across climbing frames

Vestibular hypersensitivity can lead to:

- Difficulty in changing directions and walking or crawling on uneven or unstable surfaces
- Being poor at sports
- Feeling over-disoriented after spinning, jumping or running
- Expressing fear and anxiety of having their feet leave the ground

The Senses

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Taste

Persons with ASD can be sensitive to tastes and can appear to be 'fussy' in their choice of food. They may prefer bland and uncomplicated tastes or, alternatively, eat extremely hot spicy or bitter foods.

“Sensory problems with taste, smell and texture could make certain foods intolerable and this could cause enormous problems in school where children were meant to finish everything on their plate.”

[Sainsbury, \(2000\) p. 105](#)

The Senses

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Smell

Some individuals with hyper-sensitivities cannot tolerate how people or objects smell, though their carers can be unaware of any smell at all. They run from smells, move away from people and smell may be one factor in making them insist on wearing the same clothes all the time. For some, the smell or taste of most food is too strong, and they reject it no matter how hungry they are. They are usually poor eaters, gag/vomit easily, eat only certain foods and are reluctant to try new foods.

Other individuals might chew and smell everything, using this as a main information channel. They may identify by smell and react badly when carers, for example, change perfume/ after-shave.

Some smells can be overpowering. There may be a very strong reaction to:

- Perfumes
- Cleaning liquids
- Paint
- Food, especially mixed food

People with ASD using smell as a main information channel may:

- Smell hands proffered in greeting
- Smell items (including food) offered to them
- Smell hair (even of strangers) for identification or just for stimulation

The Senses

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Pain

The person may not appear to feel pain or show distress in relation to levels of pain which others

would find unbearable.

There may also be a long (hours) delay in their reaction to a 'painful' stimulus. This can extend to temperature control. On the other hand, the person can have a very acute sense of pain and may be very fearful of injections. Sometimes, an apparent lack of responsiveness to pain is in fact a communication and social problem; the person does not see the point of calling attention to their distress or may even decide not to do so to avoid to them the further uncomfortable (even painful) experience of being physically comforted.

Auditory stimulation may cause a reaction which is equivalent to that produced by pain.

"The lack of reaction to pain can prevent the person learning to avoid certain dangerous actions, causing frequent trips to the local casualty department." - [Attwood \(1993\) p. 137](#)

The Senses

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In order to compensate for sensory differences, the person with an ASD might compensate by using other senses.

Many people with ASD touch and smell things, some constantly tap everything to figure out where the boundaries are in their environment, like a blind person tapping with a cane. Their eyes and ears function, but they are not able to process incoming visual and auditory information ([Grandin, 1996](#)).

- A person can tap objects to produce the sound in order to recognize what it is, because for him/her visual recognition can be fragmented and meaningless (although, generally vision is the preferred sense for people with ASD)

Sensory Differences - Adults

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Sensory differences are likely to remain throughout a person's life, although the form that they take and the individual's own coping mechanisms may vary widely.

More able adults may well have developed strategies to help them cope or compensate. For instance, individuals with ASD who experience light sensitivity now commonly use tinted spectacles.

Patients with ASD may make specific requests to enable them to function in the appointment room. They may require that the environment is adjusted for them and these adjustments will be critical for their functioning.

For some adults on the spectrum, the stress involved in attending a surgery will simply be too much and they may require a home visit to receive any medical attention.

Adults who have sensory differences:

- May have learnt to conceal their difficulties, so practitioners should be sensitive to the possibility, even if they have not stated that there is a sensory difficulty
- May need practitioners or carers to minimise the physical and auditory distractions during the appointment
- Practitioners need to ensure the patient is prepared for any physical contact
- A home visit may be necessary

Consequences for Behaviour

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Sensory issues can have an effect on behaviour. Hyper and hyposensitivity can lead to withdrawal from social interaction and communications and it can increase stereotypic behaviours.

For example:

- The person may become obsessed with gaining access to the sensation
- The person may find it difficult to attend to or focus on other things
- There can be an intense fear or dislike of a particular sensation
- The person can respond badly to crowded waiting rooms
- Fear of noise can be the cause of bad behaviour or tantrums (eg breaking the telephone because they think it will ring,
- making a baby cry and thus being able to predict and manage the noise that will ensue)

Consequences for Behaviour

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The sensitivities to stimuli mean that a person with an ASD can easily reach a point of sensory overload. This can occur in situations that may not cause any concern to other people. The overload comes when the person has taken in more than they can cope with.

Sensory sensitivities and the dangers of sensory overload can lead to the person 'shutting down' and withdrawing.

"... The only everyday sensory experience that neurotypical people have that is remotely similar seems to be 'rush hour'. Like computers overloaded with information and required to process too much at one time, we often 'crash'. Some people shut down and 'tune out' completely." - Sainsbury (2000) p. 101

Consequences for Behaviour

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[Bogdashina \(2003\)](#) points out that individuals with ASDs often describe 'stims' as defensive mechanisms from hyper- or hyposensitivity. Sometimes the person might engage in these behaviours to suppress the pain or calm him or herself down (in the case of hypersensitivity).

Other times, these behaviours can serve the function of arousing the nervous system and getting sensory stimulation from the outside (in the case of hypo sensitivity), and sometimes to provide themselves with internal pleasure.

Examples of 'stims':

- Tapping fingers
- Watching things spin
- Rocking
- Spinning
- Flapping hands

Consequences for Behaviour

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Temple Grandin argues that learning to recognise sensory overload is very important. It is better to prevent it than to 'deal with the consequences'. A person may need a quiet place where s/he can go to 'recharge his batteries' from time to time.

. A 'First Aid Kit' (for sensory overload) could be available. This kit could contain items such as a squeeze ball, distraction wands, attractive shapes and rattles. Each child will vary in their preferences. Practitioners (where there is advance warning) might consult with parents/carers about practical steps that can be taken.

Testimonials from people with ASD

(Page 2/18)

Many adults with ASD have described what it feels like to have an ASD from their perspective. They can provide some valuable insights. Sometimes we may need to try to transport ourselves into that world to understand the behaviours of the person.

Ros Blackburn, who is an adult with autism, says:

"To me, the outside world is a confusing mass of sights and sounds. It is totally baffling and incomprehensible. Try watching a soap opera on television with no volume. The characters' actions immediately become sudden and unpredictable since the meaning behind them is no longer clear." -

[Blackburn \(2000\) p. 4](#)

Testimonials from people with ASD

(Page 3/18)

Wendy Lawson is a high functioning woman with an ASD. Wendy has her own website where she describes some of her insights and experiences. This is the link to her website.

Reasons for Behaviour

(Page 4/18)

This different experience of the world can lead to the person exhibiting atypical behaviours. Some of these behaviours will be as a direct result of having an ASD. More able individuals may only show such behaviours in stressful situations.

Some behaviours associated with, but not exclusive to ASD:

- Flapping, rocking, skipping
- Lining things up
- Looking at things from a particular angle
- Watching things spin
- Continually acting out scenes from a particular video
- Insisting that a game is always played in a certain way
- Playing very rigidly with toys (eg lining up cars, posting into boxes)
- Insisting that stories must always be the same

Reasons for Behaviour

(Page 5/18)

Rigidity in thinking and behaviour can lead to reliance on routines, rituals and resistance to change.

This is also often described as a 'need for sameness.'

Routines are of course essential for everyone. Most people develop set times and procedures when they wash, dress, go to work and so on. It is when such habits are so fixed that they interfere with functioning that problems occur. If a person becomes so reliant on the train leaving at a certain time that he or she cannot cope if the train is delayed, then this impacts upon day-to-day functioning.

The person might:

- Create rituals and routines for themselves and be very disturbed if these are interrupted
- Insist that things are done in a certain way
- Insist on the same route to the clinic/school/work every time
- Show an unusual resistance to unfamiliar food

Reasons for Behaviour

(Page 6/18)

Rigidity of thinking and behaviour can also be expressed in terms of a lack of spontaneity and initiative. Choice can also be difficult in that it will be hard to hold two alternatives in mind at the same time. The person may appear only to be able to function on one 'channel' at a time.

For example:

- The person may have difficulty choosing activities or engaging outside their own interests
- There may be difficulties in planning activities or switching from one activity to another
- It can be hard for the person to consider alternatives or to make a decision when possibilities are open
- There might be problems in knowing what to do in unstructured situations
- It can be difficult to answer open-ended questions
- The person may be able to learn set routines and even set responses to questions, but s/he may then be unable to modify these and may become upset if asked to do so

Reasons for Behaviour

(Page 7/18)

Difficulty in understanding how others think and feel will also make it hard to predict other people's behaviour. This can result in a tendency to seek out the predictable in terms of other people's behaviours as well as a tendency to seek out what is regular in the asocial world such as bus timetables, air flight numbers and so on.

In the clinic setting, this may lead to the person being:

- Generally anxious
- Scared of the doctor or nurse
- Fearful of possible discomfort or pain
- Scared of intervention or the unknown

Reasons for Behaviour

(Page 8/18)

It can be hard to switch attention and it may take a long time to do so. This can sometimes lead to the person being perceived as being 'difficult', 'disobedient' or 'detached'.

When a person displays processing difficulties, the natural instinct may well be to repeat an instruction, often using slightly different wording. However, this can make things harder for the individual with an ASD, given that he/she now has a different instruction to process and may need to start processing all over again.

Be aware that the person can have difficulties with:

- Following a string of information
- Needing time to process concepts
- Understanding what is required
- Focusing on tasks led by others
- Being motivated to take part
- Attending to more than one thing at a time

Reasons for Behaviour

(Page 9/18)

The person may have learned set responses to questions, but s/he may then be unable to modify these and may become upset if asked to do so. Try to ask a parent/carer to help answer questions or to interpret the set responses given.

It is also useful to know how the person usually behaves so that you can know whether the behaviour displayed is unusual.

Possible consequences:

- The person may well learn in a rote way
- The person might stick to learned responses
- The person might rely on others to cue their actions and to prompt them
- The person may not be able to answer questions at all
- The person may bombard the practitioner with information but be unable to sift out the important or relevant aspects
- The person may perpetually ask questions

Reasons for Behaviour

(Page 10/18)

Another important area that might directly impact on the clinic setting is memory. There may be difficulty in retrieving memories and a failure to develop personal event memory. [Jordan and Powell \(1995\)](#) have drawn attention to the fact that the person may not be able to search their memory for personal events yet have excellent long-term cued recall for facts about him/herself.

This can make it difficult for the person to give a genuine medical history or to tell the practitioner what has happened in the past, except as a rehearsed 'fact'. A difficulty in recalling the gist of what happened can make it hard to develop a sense of overview. The person may be able to learn a list of facts in great detail but may not be able to connect them with existing knowledge patterns or even be aware of what they know.

- Memory can be extensive in terms of rote learning but the person may need cues to retrieve personal memories
- The person might not spontaneously remember what happened to them or how they behaved

- The person might find it difficult to give the gist of an event
- The person may be able to give a written account but not a verbal one

Causes of Stress and Anxiety

(Page 11/18)

There may be a variety of reasons why an individual displays certain behaviours. The meaning of a particular behaviour lies with the individual and the particular situation the person is in. Stress can intensify rigidity. One of the starting points for reducing rigidity of thinking and behaviour is to identify sources of stress.

Some triggers can be:

- Over-stimulation
- Particular phobias
- Confusion over what to do or what is expected of them
- Uncertainty or not knowing when some event will be over and what will happen next

Causes of Stress and Anxiety

(Page 12/18)

Sensory overload can also be a reason for anxiety and consequent inappropriate and self-abusive or violent behaviour. Head banging, knuckle nibbling and tantrums are a way of telling others that enough is enough.

Behaviours that signify overload:

- Pacing up and down
- Covering ears with hands
- Screaming
- Excessive spinning or rocking
- Total withdrawal
- Violence or destructiveness
- Head banging
- Self injury
- Irritability

Causes of Stress and Anxiety

(Page 13/18)

Several studies have indicated that there is a greater risk and higher incidence of depression or affective disorder in adults with ASDs.

Signs of problems arising as a result of anxiety:

- Depression
- Withdrawal or inhibition of effort
- School failure
- Job loss
- Irritability and violent outbursts
- Passivity or dependency
- Alcohol misuse (helps to overcome inhibitions but promotes inappropriate behaviour)

Causes of Stress and Anxiety

(Page 14/18)

There will be particular times in a person's life that may make it more likely that s/he will display unusual behaviours or increased anxiety, stress and possibly depression. Having an awareness of the context in which the person is, may help identify changes to behaviour.

These are likely to be associated with key transition times such as:

- Diagnosis
- Starting school
- Moving to secondary school or into further education
- Young adulthood and puberty
- Changing employment
- Death/loss of parent or carer

Causes of Stress and Anxiety - Adults

(Page 15/18)

Adults with Autism Spectrum Disorders

Where the patient is an adult with an ASD, s/he might attend appointments unaccompanied. Even if the person does attend with support, it may well be the case that s/he is otherwise coping with little or no support and this can have an impact on behaviour.

"At a recent meeting for people with Asperger syndrome in London...it was suggested that...individuals might make their own arrangements to meet...without the facilitation of staff. The suggestion was greeted with much incredulity. 'You should know' said one young man, a University student who had contributed actively to the day, 'that you might as well ask us to go to the moon.'" - Howlin, (1997) p. 257

Causes of Stress and Anxiety - Adults

(Page 16/18)

Reasons for Behaviour - Adults

The behaviour exhibited by an adult with an ASD in the appointment situation will be affected by a number of factors, both directly and indirectly related to the appointment.

Factors likely to affect behaviour:

- The person's present state of health
- The disruption that the appointment causes to their routine
- Anxiety caused by the practical aspects of attending an appointment
- Stress at the social demands being placed on them (eg sitting in a small consulting room, being looked at and asked questions, tolerating physical contact)
- Whatever problems the person may have encountered en route to the appointment.

"As people with autism we tend to find our sense of security in our rules, rituals and continuity of roles...Therefore it is very distressing when life does not go according to our expectations..." - Lawson (2001). p. 29

Causes of Stress and Anxiety - Adults

(Page 17/18)

Behaviours as Coping Strategies - Adults

It may be that combined challenges have overridden their physical symptoms or discomfort, and they may need time and help to focus on the reason for the consultation.

In some cases, a patient may displace their anxiety by becoming upset with some aspect of their treatment. This can manifest itself as rudeness or even aggression. The social difficulties caused by autism spectrum disorder can make it difficult for individuals to assess how others perceive their behaviour.

Behaviours associated with stress in appointment situation:

- Not wanting to sit or be still
- Evasive tactics (eg asking to go to the toilet)
- Seeming unhappiness with an aspect of the appointment (eg treatment by the receptionist)
- Repetitive questioning
- Passive attitude
- Forceful, rude or even violent attitude
- Delayed or no response to questions
- Co-operating fully but close questioning reveals a lack of understanding
- Booking in but then leaving before gaining consultation
- Having repeated number of appointments without arriving because could not enter the building for a number of reasons

Causes of Stress and Anxiety

(Page 18/18)

Many people with an ASD stress that they perceive the world in a different way from others and that the world is not adapted for people with ASD. Understanding and adapting the environment can therefore make a large difference to how well the person functions.

“The problems arise not so much from Asperger's syndrome itself, as from a social world which is not designed for people with Asperger's syndrome but for people who think and perceive the world in very different ways.” - Sainsbury (2000). p 27

Topic Two : Practical Strategies

A: Routine medical management

B: Recognising and dealing with stress in the individual

C: Strategies for encouraging communication

A: Routine medical management

Routine Procedures

(Page 2/23)

There are a number of routine procedures undertaken on a regular basis in settings that can pose a challenge to the patient with an ASD. The patient with an ASD may experience what is happening in an adverse way and his/her response may not be what practitioners typically expect.

Possible reasons for an Adverse Response by someone with an ASD

- S/he does not know what to expect
- S/he may feel that his/her space is being invaded
- The approach may be causing actual physical pain/ discomfort (although it would not do so to someone with less hypersensitivity)
- S/he may be frightened by an instrument/ implement s/he has not seen before

Routine Procedures

(Page 3/23)

It is important to make sure that the patient with an ASD feels as comfortable as possible before the procedure begins. Spend time reassuring them about what is going to happen. If s/he is too young or does not speak, there may be a means of symbolic communication that the patient uses. A parent/carer who is accompanying the person with the ASD is likely to be in the best position to know how to keep the situation as calm as possible.

Ways to approach

- Allow time to settle
- Talk quietly and slowly
- Use simple words
- Check the patient understands or work through an intermediary
- Check on how the person feels or work through an intermediary
- Explain what you are going to do
- Show the person any equipment you are going to use and allow them to touch the items
- The practitioner might do a mock demonstration on him/herself or the patient's parent/carer
- Ask if the person is ready

Routine Procedures

(Page 4/23)

It will be important to secure the comfort and confidence of the patient with an ASD in what the practitioner is proposing to do. Failure to do that may mean the procedure has to be postponed because the patient is too upset.

The practitioner should take the lead from the patient, checking if s/he is able to articulate how s/he is feeling or if the patient knows how to stay calm. Always ask first, but if that does not work, then ask the parent/carer how to approach the patient.

Making the procedure clear

- Ask the patient with an ASD how s/he is feeling
- Use basic short sentences
- Be prepared to draw, manipulate pictures or physically demonstrate what is needed.
- If the patient cannot tell you, ask the parent/carer what has worked in the past and how the person should now be approached.
- May require a number of visits to familiarise and condition the patient to the surgery.
- Be prepared to abandon the consultation early if the patient becomes distressed.

Routine Procedures

(Page 5/23)

If the patient is already physically stressed then it may be necessary to wait until s/he is calmer in order to get a true picture of his/her health (e.g. by taking his/her blood pressure) or to gain his/her confidence in doing any physical examination.

Use simple de-stressing exercises focussing on breathing and posture to help the patient calm down. Ask the parent/carer what helps the patient to stay calm and use that, if appropriate. Only proceed with the intervention once the patient s/he looks or says s/he feels calmer.

Calming techniques

- Have simple 'de-stress' toys available – squeeze balls, marble runs, objects to twirl or twiddle.
- Ask the patient to breathe slowly and deeply and the practitioner then attempts to control the rate by slow counting.
- Involve a parent/carer, if present, in employing calming techniques
- Concentrate on relaxing shoulders and facial muscles by flexing and releasing.

Routine Procedures - Adults

(Page 6/23)

Medical appointments will inevitably involve the disruption of normal routines and this is likely to be a source of anxiety for the patient with an ASD.

In addition, even adults with a good level of functioning may well find the practicalities of getting to an appointment on time a considerable challenge.

Consider:

- Whether the venue and time of the appointment is likely to be problematic for the individual
- The potential impact of anxieties related to attending the appointment

- Identifying what individuals and agencies, if any, are supporting the patient
- Offering an appointment time during a quiet part of the day or outside of usual appointment times

Routine Procedures - Adults

(Page 7/23)

Although individuals do generally learn to cope with non-routine appointments, they may only be able to endure one such intrusion per day, or even per week. Any regular treatment programme will need to take this into account, or the patient may simply not be able to attend.

A home visit may be a necessary option for some patients. If so, there are important considerations surrounding the invasion of personal space that is inevitable. Often, individuals with ASD lead fairly solitary lives and are not used to visitors in their home. Their personal environments need to be treated with respect. They may have collections of everyday items which are untidy or even unhygienic, but which are valued highly. It may be necessary to ignore such unusual aspects of the environment if a successful consultation is to take place.

Consider:

- Checking that appointments are planned wherever possible to avoid too many appointments close together, thus *overloading* the patient
- Arranging home visits to minimise disruption and distress for the patient
- Referral to appropriate support agencies if a home visit reveals health or welfare issues

The Consultation - Adults

(Page 8/23)

An adult patient will have experience of Medical appointments and examinations. However, s/he may have developed specific fears as a result of previous bad experiences and it will be important to gain this information and be sensitive to it.

Where the patient is supported, the parent/carer should be able to offer guidance on the best approach for that individual.

However, it is important to direct communication to the individual, rather than to the parent/carer, as much as possible.

However articulate the patient is, s/he is likely to be highly anxious and may have difficulty explaining his/her symptoms, asking appropriate questions and absorbing information. S/he may well require a longer consultation than is usual, to allow for these difficulties.

Consider:

- Gaining information from parent/carer (or the individual themselves) in a manner that preserves his/her dignity
- Consider telephoning parent/carer prior to the appointment to obtain background information which would facilitate the appointment.
- Communicating directly with the patient wherever possible
- Checking the patient's understanding by asking simple, but not leading, questions and allowing time for information to be absorbed
- Planning the appointment carefully to ensure the patient is not rushed.

Physical Examination – Ear, Nose And Throat

(Page 9/23)

Routine physical examination may be needed to confirm or rule out any possible conditions. The patient with an ASD may need an ear, nose and throat examination. Ask the patient or his/her parent/carer if s/he has had that procedure before. This will help to establish whether s/he knows what to expect in this examination and will give guidance on whether s/he may react adversely.

It will be helpful for patients with ASD to see what implements are to be used and to know the order in which they are going to be used.

Basic checks

- Ask if s/he has had an ear, nose and throat examination before
- Use simple words

If YES

- Recap on the basic procedure and tell the patient the order in which it is going to proceed.
- Show the patient the basic implements and ask if s/he is ready
- Explain one task at a time and keep it simple to avoid causing stress
- Talk quietly to the patient telling them what you are doing as you undertake the task

If NO

- Show each implement in turn and explain where it will be placed and what for, in simple terms
- Put each implement in a visual order so that the patient can anticipate what is coming next
- Use numbers/colours to reinforce that order if needed.
- Start with the least intrusive implement/examination
- Repeat and reinforce the order of the examination in clear simple terms as it proceeds.
- Remove each item in the visual order as it is used.
- Be prepared to postpone the examination if the patient becomes distressed.

Physical Examination–Temperature and other visual checks

(Page 10/23)

The taking of a Blood pressure reading can follow the basic guidelines of asking, checking, explaining and reinforcing. The feeling of the cuff whether manually or electronically inflated may need a demonstration and further explanation in order to prepare the patient for the constriction of his/her arm. Show the patient the equipment and explain in simple terms what is going to happen. Ask him/her to tightly squeeze his/her arm to demonstrate how the cuff will feel. If using a manual device it may be helpful to demonstrate the noise the monitor will make when it is used.

Take guidance from the patient or his/her parent/carer on how to proceed. For patients with ASD who can understand, a basic explanation about the instrument may also be beneficial.

Physical Examination–Temperature and other visual checks

(Page 11/23)

Measuring body temperature will be greatly eased by employing one of the types of non-intrusive

thermometers. Children with ASD will be familiar with the use of forehead checking in the home, but it may be wise to check with his/her parent/ carer first on how temperature is taken. As with other procedures, ask, check, explain and reinforce before beginning the taking of temperature.

For visual checks on eyes, hands, nails, glands, before approaching the patient with an ASD, make sure that s/he knows what is going to happen. Practitioners need to show them, by demonstrating on themselves or his/her parent/carer, exactly where they will be looking and where they will be placing their hands.

Where the patient over-reacts to such an approach :-

- Ask him or her if they are ready
- Try to ensure the person is not additionally stressed
- Ask the parent/carer if s/he can assist
- Be prepared to postpone the examination, if there are signs of distress.

Guidelines

A - ASK

C - CHECK ON UNDERSTANDING

E - EXPLAIN WHAT IS HAPPENING

R - REINFORCE AND REPEAT - WHAT IS HAPPENING AS IT IS DONE, USING A SLOW, CALM VOICE

Physical Examination - Full

(Page 12/23)

The patient may require preparation in advance if a full physical or intimate examination is required. Ensure that there is enough time to conduct the procedure (e.g. give a double appointment).

Reasons for potential problems

- Full or intimate examination requires a degree of intrusion
- It can make the patient feel vulnerable or uncomfortable
- It may cause pain/discomfort
- The situation is unfamiliar
- The stress from all or any of the above causes may prohibit a successful procedure.

Physical Examination - Full

(Page 13/23)

Where information in advance is not an option, tell the patient what is needed but the consultation should not be rushed.

Give clear and simple information and a demonstration of where the patient needs to be and what they need to do.

Consider having de-stressing techniques or aids available and ask parent/carer how the patient can be made as comfortable as possible. If a parent/carer is present then enlist his/her help and support to make this procedure as easy as possible. A diversion – a book, toy or Walkman may assist in making this procedure straightforward.

Strategies that may help

- Advance warning
- Clear, simple demonstration and explanation
- Access to a de-stressing aid
- Access to a diversion
- Support from a parent/carer

Treatment - Adults

(Page 14/23)

The process of following treatment can be problematic for adults with ASD. The list below cites skills commonly needed, which may be limited for adults with ASD and cause a treatment plan to fail.

Individuals may need support to :

- Select the most appropriate treatment option for them;
- Regard treatment as a priority (and therefore recognise its relation to his/her state of health);
- Understand treatment instructions;
- Remember when treatment is scheduled;
- Have the practical skills (eg dexterity to apply ointment) to follow treatment;
- Have the discretion to judge when treatment should be followed rigidly (eg anti-depressants) and when flexibly (eg. skin creams);
- Assess whether the treatment has been beneficial.

Consider:

- Explaining clearly but simply the implications of different treatment options
- Explaining the consequences of declining treatment or following treatment incorrectly
- Giving clear, instructions, supported by written or visual forms
- Supervising the patient taking initial treatment to assess his/her competency
- Providing a medication box or other means of prompting
- Agreeing how treatment is to be monitored so that the patient is not reliant on recall (eg. a brief diary to be completed daily)
- Agreeing a clear follow-up plan (see next)

Follow Up - Adults

(Page 15/23)

An effective follow-up plan is vital for the adult with ASD

Whilst under normal circumstances the onus would be on the patient to follow up an appointment and/or flag up any problems, this system cannot be relied upon for individuals with ASD.

As above, treatment can fail for many reasons and at any stage. A clear follow-up strategy will provide a vital safety net.

Consider:

- Seeking the patient's permission to involve others in the monitoring of treatment, whether this is parent/carer or partner
- Providing the patient and/or parent/carer with a summary of key points in writing. This will enable the patient to
- revisit and clarify these points as necessary
- Agreeing a strategy of what the patient should do if treatment is not effective (including clear guidance on how long recovery is expected to take)

- Where treatment involves a number of meetings, following a similar format at each appointment to provide structure and clarity
- Reminding the patient of their upcoming appointment by a telephone call or letter.

Developmental Checks

(Page 16/23)

Taking a full medical history

This should be approached in a logical and systematic way. The basic guidelines of clear literal questions will help to compile an accurate record.

The patient with an ASD may have a poor or incomplete memory of his/her childhood and it may be necessary to ask for another source for this information. Questions about childhood diseases and infections may not be understood; give fuller information if you can. The patient with an ASD may have very accurate information on dates and times when s/he needed to be admitted to hospital, but a sketchier memory of why. If information may need to be followed up.

Asking questions

- Keep the voice even and measured
- Ask factual questions – “Have you had this rash before?”; “Have you recently been abroad and where?” to help determine patient circumstances.
- Do not ask for information that requires interpretation
- If the patient with an ASD does not know, ask them for another source – e.g. family member
- Avoid questions that require them to surmise or put the point of view of someone else

Developmental Checks

(Page 17/23)

Height and weight

Taking the height and weight of individuals with ASD may pose very little challenge to the patient with an ASD as these are familiar routines in the home.

However, the equipment may differ from the instruments the patient is used to. This could cause confusion and anxiety and the patient may not recognise your instruments. Be clear in the explanation and use a demonstration of what the patient needs to do and how the instrument will provide a reading.

Where the individual is a child, you may need to enlist the support of his/her parent/carer to be weighed with them or use a wall, door frame or visual height chart to provide a height measurement.

Developmental Checks

(Page 18/23)

Reflexes

Eliciting the reflex response may cause puzzlement and anxiety to the patient with an ASD.

It could be difficult to undertake if the patient is not fully relaxed. A high degree of skill may be needed in this situation.

A slow and careful approach, with an explanation will be helpful to the individual. Demonstration of the procedure on a parent/carer may be helpful. A fuller explanation of why the body responds at reflex points without our conscious desire will also help the able patient with an ASD to accept the approach.

Developmental Checks

(Page 19/23)

Other checks

The process of gaining medical information may also include other measurement such as that of head circumference.

The guidance given so far will help to compose questions that will elicit clear and literal answers. Where any kind of instrument, measure or piece of equipment is involved, keep the guidance opposite in mind to help clarify the purpose and procedure to ensure optimum cooperation.

GUIDELINES

A - ASK

C - CHECK ON UNDERSTANDING

E - EXPLAIN WHAT IS HAPPENING

R - REINFORCE AND REPEAT - WHAT IS HAPPENING AS IT IS DONE, USING A CALM, SLOW VOICE

Medication

(Page 20/23)

The majority of people with ASD will have taken oral medication at some point in their lives, even if it is only basic pain relief. For some, taking a range of supplements orally or ingesting tablets will be no problem. Ask the patient with an ASD or his/her parent/carer how s/he would prefer to take his/her medication. Be specific about explaining how tablets may be taken.

It could be that a liquid would be preferable. Ensure that the dosage is explained clearly and give other verbal or written information on what to do if the symptoms persist.

Ointment

The practitioner may have to make a judgement on the likelihood of the ointment staying in the body area for a sufficient period of time to be effective. Where a patient with an ASD is bothered about personal invasion then the prescription of ointments may not have the desired outcome. Taking guidance from the patient or his/her parent/carer will help with the decision.

Ensure that the dosage is explained clearly and guidance is given on how much to apply. Give other verbal or written information on what to do if the symptoms persist.

Skin sensitivities

Ask if the patient reacts strongly to textures and sensations on the skin.

Observe how comfortable the patient is in his/her clothing and how s/he responds to touch.

If there is no/little sensitivity

- Explain about the prescription of cream/ointment and how to apply it

If there is sensitivity

- Ask about previous prescription of cream/ointment
- Suggest disguise or subterfuge – e.g. under a bandage or stocking, only at night
- Consider oral medication to combat symptoms

Medication

(Page 21/23)

Liquid/Medicine

It may be unlikely that the patient with ASD has not had oral liquid medication in his/her lifetime. However, the adult with an ASD may need the same consideration of taste and smell that could apply to a much younger person. Heightened sensitivity to taste and smell may make stronger/more adult medication hard for them to ingest. Consider prescribing a more child-friendly medication or look at other forms of prescription, e.g. tablets or capsules.

Ensure that the dosage is explained clearly and give other verbal or written information on what to do if the symptoms persist.

Medication

(Page 22/23)

Parenteral (intra muscular, subcutaneous, intravenous)

Intravenous medication is usually only given in practice in an emergency such as a life-threatening anaphylaxis or severe pain.

In this situation there would be no time to condition the patient to the procedure. It is therefore best performed quickly and efficiently by an experienced practitioner.

Vaccines are given by intramuscular injection and most of these schedules will occur prior to diagnosis of ASD. Vaccinating older individuals will pose a challenge. Local anaesthetic creams applied prior to the procedure may well reduce pain.

Possible reasons for an adverse response

- S/he does not know what to expect
- His/her space is being invaded
- The approach may be causing actual physical pain or discomfort
- S/he is frightened by an instrument/implement s/he has not seen before
- There is some sensory problem

Medication

(Page 23/23)

Other

The administration of any kind of medication requires thought and flexibility on the part of the medical practitioner.

Techniques and strategies that are used with much younger individuals may still be needed with adults with ASD and this should not be seen as demeaning or inappropriate. If the net outcome is that the patient accepts medication, then that is a successful conclusion.

Examine what s/he is already used to and tailor the prescription to that.

Checking

- Ask what s/he is taking/have taken
- Take time and care
- Tailor your prescription to what is familiar, if possible

B: Recognising and dealing with stress in the individual - introduction

Stress and the patient with an ASD

(Page 2/29)

The way in which patients with ASD may display signs of stress and anxiety may not differ greatly from anyone else. The basic signs of increased respiratory rate, pallor, sweating, and increase heart rate, along with the inability to be diverted the patient from their preoccupation may hold as true for someone with ASD as anyone else.

However, s/he is more likely to display a range of other indicators, some of which may make it difficult to understand his/her meaning and may cause misunderstanding of his/her emotional and physical state.

Given the likelihood of chronic stress in individuals with ASD, some of these signs maybe present in their apparent resting state.

Indicators of stress

- Quick and shallow breathing and irregular pattern
- Increased heart rate
- Sweating
- Restlessness
- Pallor
- Poor sleep patterns
- Poor eating habits
- Inability to be diverted from emotional and physical state
- Tearful
- Irritability

Typical Indicators of Stress

(Page 3/29)

Quick and shallow breathing

The regulation of breath control is something that can be very variable among patients with ASD (as with others). The depth of breathing may be different according to a range of emotional states. For instance, shallow breathing may also be associated with anticipation and great excitement or intense

pain. Sighing and irregular respiration is a well recognised sign of stress and is worth noting. Their varied use of breathing may also be in relation to concentration, awareness and relaxation.

Consideration should also be made for the co-morbid conditions of asthma and allergies that may co-exist.

Ways to check

- Ask the patient to concentrate on his/her breathing
- Demonstrate what is wanted and emphasise the timing by slow counting.
- Suggest s/he puts a hand on his/her chest while s/he is doing slow breathing
- Check with him/her or his/her carer if this breathing pattern has been different.

Typical Indicators of Stress

(Page 4/29)

Increased heart rate

Section 1 of this topic deals with ways to relax the patient with an ASD in order to get a typical blood pressure or pulse reading. An increased heart rate may be related to the anxiety s/he is feeling or the approach of someone s/he does not know (well).

Ways to check

- Ask if s/he has had difficulty with associated functions – shortness of breath, light headedness.
- If you cannot get a representative reading, suggest home monitoring of pulse or blood pressure.

Typical Indicators of Stress

(Page 5/29)

Restlessness - see also sleep patterns below

The patient with an ASD may be exhibiting extreme agitation with an inability to sit still or attend to what is being said. This may be an adverse reaction to the experience rather than a global stress response. Give him/her time to settle or suggest a diversion to occupy him/her before using the checks opposite.

Ways to check

- Ask the patient to sit quietly
- Check for information on the levels of concentration and attention by asking the patient or his/her carer
- Have an accessible de-stressor at hand – marble run, book, stress ball
- Ask about general routines and how s/he is sleeping, eating, watching TV, using the computer etc.

Typical Indicators of Stress

(Page 6/29)

Poor sleep patterns

The differences in sleeping patterns of patients with ASD are covered in more detail in the [Health Issues section](#). There are no “typical” sleeping patterns of people with ASD, but many do experience

sleep disruption or do not sleep for prolonged periods or through the night.

Ways to check

- Be explicit with the patient with an ASD or his/her carer when talking about how s/he sleeps at night
- Be explicit about whether his/her sleeping habits have been different recently – give examples of what you mean (eg how often do you wake; how long do you sleep for; what do you do when you are awake?)
- If yes, ask how they feel their sleep has been affected

Atypical Indicators of Stress

(Page 7/29)

Rocking

The action of rocking one's body or upper torso as an emotional response to anxiety or other difficulty is common to all humans. Where the patient with an ASD may differ is that this can be a regular action and it can dominate for prolonged periods. It can also be a severe extreme of rocking and involve other repetitive actions.

Rocking may be a pleasurable response or a familiar gross motor action but it may also indicate stress.

Ways to check

For these and other atypical behaviours, it will be necessary to establish

- Whether this is a new behaviour
- If it follows a pattern related to events, people, circumstances
- The frequency of the behaviour
- The severity of the behaviour
- Any physical harm resulting from the behaviour

Atypical Indicators of Stress

(Page 8/29)

Repetitive actions

Many patients with an ASD have a repertoire of actions or activities that they like to repeat in a particular pattern. These actions may involve "props" – like pieces of string, collections of objects, the visual look of an arrangement of things, mechanical toys or equipment.

These actions may be completed by the use of the arms and hands but s/he may also have other actions that engage the whole body – like crossing the room in a certain way, only treading on whole paving slabs, turning themselves round twice before walking forward. Repeated actions which have an extreme intensity and an inability to engage in other tasks may indicate stress.

Ways to check

For these and other atypical behaviours, it will be necessary to establish

- Whether this is a new behaviour
- If it follows a pattern related to events, people, circumstances
- The frequency of the behaviour
- The severity of the behaviour
- Any physical harm resulting from the behaviour

Atypical Indicators of Stress

(Page 9/29)

Head banging

Banging of the head or any part of the body, may be a part of a repeated action. However the sudden development of banging can indicate physical pain (the pain from banging masks the other pain) or maybe a response to stress.

A physical examination may provide information as to which area is affected (bruising, swelling or redness).

Look for something that is new or different

It is important to intervene in severe cases of head banging or where the individual is using this to influence the behaviour of others. This is to avoid injury which may have serious side effects (e.g. detached retinas). Parents/carers should be referred to behavioural support services and, as a short-term measure medication may be warranted.

People with ASD cannot be relied upon to limit self-injurious behaviour without support

Atypical Indicators of Stress

(Page 10/29)

Twiddling

The twiddling of objects, that may seem purposeless, is a common feature of many patients with ASD throughout their life span. The comfort that this repetitive action gives the patient serves to calm and take stress out of situations. Popular choices are pieces of string or wool, paper and mechanical objects. Twiddling also serves to occupy the mind and block out unwanted interaction with others.

Sudden or increased development of twiddling may indicate that the patient is in need of a more intense way of de-stressing.

Atypical Indicators of Stress

(Page 12/29)

Obsessions and special interests

Many people with ASD have the capacity to develop certain areas of knowledge or skill into a special interest. Like Dustin Hoffman in the film "Rain Man" s/he can memorise facts and possess an encyclopaedic knowledge of his/her chosen subject.

Patients who do not communicate will also demonstrate that they have an in-depth knowledge of a subject by the way they can manipulate equipment (e.g. computers, taps, toy cars).

Where the special interest dominates the waking time of the patient with an ASD, it may mean that s/he wishes to block out some unpleasant stimulus. This includes stress.

Look for changes in responses

Atypical Indicators of Stress

(Page 13/29)

Need for the familiar

Patients with ASD have a strong preference for the familiar and routine. This represents security and safety to him/her. When you are looking for stress reactions, it may be useful to have an idea of how the typical day goes for patient with an ASD.

Familiarity and security will underpin many of the activities and events. Where the patient is ceasing to care for him/herself or is engaged in repetitive tasks that dominate his/her day and this is unusual for him/her, s/he may be reacting to something that is causing him/her stress.

Look for changes in responses

More unusual and idiosyncratic responses

(Page 14/29)

Laughter

The variety of responses that a patient with an ASD may give to stress may make it very difficult for practitioners to recognise. One unexpected response may be what may appear as a reversal of typical emotional reactions. The individual may laugh when in pain (although the 'laughter' may be a fear reaction), and cry with excitement. Laughter may act to release endorphins to combat stress or as a way of defusing tension.

Look for extremes of inappropriate responses

More unusual and idiosyncratic responses

(Page 15/29)

Extremes of emotion

People with ASD may not learn conventional ways to express emotions, nor how to modulate their levels of arousal. They may be very delayed in developing awareness of their own emotions also, so that reactions are not modified by cognitive appraisal of the situation.

This may result in behaviours that are not only inappropriate to the situation but also extreme in their manifestation.

Look for extremes of inappropriate responses

More unusual and idiosyncratic responses

(Page 16/29)

Echolalia

Immediate or delayed repetition of sayings or words can be a feature of ASD. The patient may have developed a liking for particular words and phrases or have favourite films or TV programmes whose phrases s/he has committed to memory. The reproduction of phrases or sayings may have a resonance with the situation s/he find his/herself in or it may have no relevance at all.

Immediate echolalia can also mean that s/he has not fully understood what is said to him/her, or is

seeking control of the situation. Some may use echoing of a conversation (including both contributors and non-speech sounds like throat clearing) as a way of gaining or controlling attention.

Constant echolalia, that has not been present before, may indicate feelings of anxiety and stress.

More unusual and idiosyncratic responses

(Page 17/29)

Obsessive Compulsive Disorder

Repertoires and routines (especially when the individual is stressed) may look very much like OCD – hand wiping, clothes straightening, tidying. There will need to be a check on whether these actions have always existed for the patient with an ASD or if these are new.

The line between routines and familiar actions and OCD may overlap for the individual but prior knowledge and the other evidence you can access may help the decision.

Check for OCD behaviours by making a judgement of whether the behaviour is done for enjoyment and/ or reduction from stress. This is then likely to be a feature of ASD.

If, however, the behaviour appears to be ‘driven’ so that its performance increases, rather than decreases, stress, that is likely to be an OCD. The patient may then need referral for treatment if it is persistent enough to significantly impair functioning.

More unusual and idiosyncratic responses

(Page 18/29)

Passivity

Some individuals with ASD become extremely passive, much more than is typical and appropriate for the circumstance. The common view of ASD is of a restless and active patient. Yet some patients with ASD in a clinic situation may be very passive and allow the practitioner to approach and examine them without a reaction. Passivity can be a sign of depression and low self-esteem, which may have its origins in stress or fear. It can also be an instinctive survival response.

Is this typical of the patient?

More unusual and idiosyncratic responses

(Page 19/29)

Self-harm

Self-harm in the form of self-stimulatory behaviours can be a feature of ASD. Particular physical mannerisms may fulfil the function of self-stimulation (see related section on [Sensory Issues](#))

There may be areas of the body where self-stimulation verges on self-harming rituals – these could include biting the backs of hands, constantly picking at scabs or hitting the head or other body area. Obvious marks and old wounds are likely to indicate that this is a “stimming” behaviour (see related section on [Sensory Issues](#)). Sexual behaviours (see related section on [Emotional issues and mood disorders](#)) may also lead to self-harm but it is unlikely that these will be deliberate. Self-harm that has its roots in anxiety and depression may be hard to detect but direct questioning of the patient may lead to further information.

Ask direct questions

- Is there somewhere you have hurt yourself?
- Show me how you made this injury?

More unusual and idiosyncratic responses

(Page 20/29)

Anything that is not usual for him/ her

This catch-all descriptor covers most symptoms/indicators not already dealt with. The best way of making a diagnosis of, or eliminating, stress as a cause is to check current presentation of the patient with an ASD against what is known of his/her typical pattern of responses.

A change in behaviour and reaction is often a strong indicator that something has changed for him/her. If information is not forthcoming at one appointment, then take time to ensure that further information can be provided from consultation and asking relevant questions of the patient and the people who know him/her best.

Check for changes in behaviour and health

This may be a clue to something being wrong

Recognising and dealing with stress - adults

(Page 21/29)

Manifestations of Stress

The general guidance on indicators of stress apply equally to adults and children.

However, adults with ASD will often have developed good daily living and superficially good communication skills.

These can serve to mask their difficulties. S/He may be struggling to control his/her stress levels, and unfortunately in these situations, stress can manifest itself as anti-social behaviour.

Anti-social manifestations of stress:

- Rudeness
- Lack of compliance
- Blaming others
- Questioning of authority
- Anger or aggression

Recognising and dealing with stress - adults

(Page 22/29)

Dealing with Anti-Social Manifestations of Stress

It is important to recognise when anti-social behaviour is actually a manifestation of extreme stress. This is an indicator that the patient is overloaded and may be close to losing control. A low arousal approach will often be effective in supporting the individual to use their own coping mechanisms to calm themselves.

Where the individual is supported by a parent/carer, they are likely to adopt a 'hands-off' approach for this reason.

Helpful Strategies:

- Maintain an appropriate (approx 4 feet) distance to avoid invading personal space
- Respond in a quiet tone
- Respond calmly and slowly
- Use minimal eye contact
- Allow time for the individual to focus on their own calming techniques (time alone in a room is sometimes helpful)
- Repeat (if necessary) using the same words/phrases

The dimension of sensory sensitivities

(Page 23/29)

The seven senses

The work of people on the autism spectrum has increased our insight into the experiences of people with the condition (Williams, 1998). What has helped the understanding is the notion of the range of sensory differences that people with ASD report having. All of the senses can at one time or another be affected by distortions and disturbances, making his/her experiences very different from ours.

The work of Bogdashina (2003) has helped us to recognise that there are seven dimensions to sensory differences for people with ASD: -

1. **Vision**
2. **Hearing**
3. **Touch**
4. **Smell**
5. **Taste**
6. **Awareness of joint and muscle position**
7. **Awareness of balance from middle ear**

- Sensory differences do not form part of the diagnosis of ASD
- Many patients with ASD may also experience a range of sensory differences from typically developing individuals
- These differences may be under or over-developed – hypo or hyper
- There may be an inconsistency of perception ([Bogdashina, 2003](#)) with the patient experiencing different sensory extremes at different times.

The dimension of sensory sensitivities

(Page 24/29)

Visual Distortions

Some people with ASD say that their sight can give them the perception that everything seems to taper down in dimension or that things can look longer/bigger/smaller/shorter than they actually are. Most will say that this is not a perpetual way of perceiving the world but that distortion can happen from time to time and cause him/her deep anxiety. Others will find it hard to focus directly on things and prefer to use peripheral vision. All of these things combine to give some differing visual perceptions of

situations.

Dyslexia is a condition often associated with ASD. Coloured lenses are marketed with claims for helping both conditions and many individuals with ASD claim great benefit from them in getting rid of visual distortion.

It is quite common for people with ASD to have some strong likes and dislikes in terms of patterns, colours and sequences.

The patient with an ASD may like things in a visual order to his/her own preferences and standards.

Checks for hypo and hyper-sensitivity

- Bright light may cause discomfort
- Dark rooms may mean it is hard to discern what is there
- Fluorescent lighting can distort images or be too distracting because of the noise or flicker of the tube
- Corridors with no obvious exits may be frightening
- Peripheral vision may be more comfortable than a direct focus
- But peripheral vision may mean the patient misses the foreground
- Direct mutual eye gaze can cause discomfort and stress

Many of these differences may not be immediately obvious.

Be aware that these may be a cause of additional stress

The dimension of sensory sensitivities

(Page 25/29)

Hearing

Hearing anomalies: It may be hard to know whether the patient with an ASD is hearing instructions. His/her attention can appear as if it is elsewhere, but is able to act upon the instruction perfectly. Often individuals with ASD respond in an under or over reactive way to different auditory stimuli. They may have an acute awareness of noises that are not generally noticed (e.g. a computer's fan). The patient with an ASD may hold his/her fingers over his/her ears or partially cover the outer ear, and this is a virtually certain sign that his/her auditory sense is overloaded.

Checks for hypo and hypersensitivity

- Appears not to be hearing what is said
- May be distracted by peripheral noises – lights, computers, clocks
- Ears are covered totally or partially by hands
- Inability to filter human voices from background noises
- Repetitive noises or actions are used to mask auditory distress

The dimension of sensory sensitivities

(Page 26/29)

Touch

Tactile defensiveness

This is an over-reaction to any type of unwanted tactile sensation. Some people with ASD report feeling

assaulted by the touch of others and this can be apparent when they are touched when not expecting it. Many say that firm holds and grasps are preferable to lighter stroking and gentler touches.

Tactile intolerance

People with ASD also find some textiles and other tactile experiences difficult to bear. It is common for people with ASD to dislike new clothing. The level of intolerance would include not being able to wear certain fabrics, like wool and other itchy textiles or being unable to tolerate the feel of seams, welts, cuffs, ribbing or manufacturer's labels in the neck or side seam of a garment.

Checks for hypo and hypersensitivity

- Their choice of clothing may reveal an intolerance to certain textures or fastenings
- An over-reaction to gentle touch
- Seeks out particular tactile experiences – squeezing your hand)
- Hyperactive behaviour that is seeking particular tactile responses eg persistent rubbing or picking
- 'Different' in their response to hot and cold
- Lack of response to injury and pain

The dimension of sensory sensitivities

(Page 27/29)

Taste and Smell

Taste/Smell predominance

The patient with an ASD is likely to have developed some strong preferences for particular tastes and smells. It may be difficult to introduce new taste experiences or deviate from 'tried and tested' medication.

Taste and smell may predominate in the way the patient with an ASD gains information about the world. They may insist on tasting anything new or smelling everything before complying with an instruction (this obviously has to be with discretion).

Checks for hypo and hypersensitivity

- Patient may need to smell materials or new equipment
- May respond adversely to smells of perfume/air freshener that s/he finds over-powering
- May have an over-reaction to tastes and smells that have a negative connotation
- May taste inappropriate substances e.g. soap)
- Often do not like mixed textures in foods

The dimension of sensory sensitivities

(Page 28/29)

Awareness of joint and muscles - Proxemics and Proprioception

Proxemics refers to the way in which we position ourselves in space and time and know from childhood how to keep a suitable distance from others. This will include what is a "suitable distance" from those we know and love and also from those who are strangers and potentially threatening.

Differences in proxemics and body awareness may affect the how the body is orientated in space, and the amount of awareness the patient with an ASD has of objects, furniture and people around him/her.

S/He may have his/her own fixed sense of personal boundaries but not be able to respect others' professional distance boundaries.

Proprioception refers to feedback from muscles and joints that helps the individual, maintain posture and be aware of limbs and body in space.

Checks for hypo and hypersensitivity

- Over-reaction if the distance between them and others is too far away or too close
- Needing to be told where to sit/stand/lie
- 'Clumsy' movements around the clinic (eg bumping into clear obstacles)
- Walking' through other people as if they are not there

The dimension of sensory sensitivities

(Page 29/29)

Awareness of balance - Vestibular

Vestibular sense is our innate sense of balance and knowing our capacities in exploring new experiences. Patients with ASD may crave 'risky' sensations, such as balancing on thin supports or climbing to the top of precarious heights. This ability is linked to his/her vestibular sense and s/he appears to lack fear of danger or falling. Often children with ASD love spinning, rocking, seesawing, hanging upside down and fairground rides such as the Waltzers, They are seeking out experiences that stimulate balance mechanisms and give him/her an extreme sensory high that day to day physical movements do not. These may be activities that also appeal to the adult patient with an ASD who is experiencing stress.

Checks for hypo and hypersensitivity

- Note choices for sitting and standing and any accompanying movements
- Perching, rocking and leg swinging may be an acceptable alternative to more risky sensations
- A stress reaction may involve a 'break-out' movement that replicates more precarious activities

C: Strategies for encouraging communication- introduction

Basic differences in receptive and expressive communication

(Page 2/21)

The impact of the triad of impairments on the acquisition, use and understanding of language can be substantial in the patient with an ASD. Not only does the area of impairment in communication have repercussions on development, but also the impairment of social interaction may override any form of communication the patient has. Communication and social interaction impairments may affect the entire presentation of the patient during an appointment.

- Communication includes all aspects of understanding and use of a means to express oneself
- Communication covers all forms of verbal and non-verbal expression and comprehension
- The patient with an ASD who has good vocabulary and speech may still not use it to

communicate

Basic differences in receptive and expressive communication

(Page 3/21)

The [diagnostic criteria](#) (Topic 4 section A) for qualitative impairment in social interaction indicates how this can impact upon the development of communication.

The patient with an ASD may not appreciate that there is a need to communicate, nor understand the social conventions expected in a clinic setting

There are impairments in

- The use of non-verbal expression (appropriate eye contact, facial expression, gesture and body posture) and the social timing of these; thus, communication appear odd or awkward
- Social and emotional reciprocity, which may mean the person with an ASD cannot engage in social dialogue, aimed at putting the patient at ease
- Relationships, which may mean the patient with an ASD cannot understand and adopt an appropriate role in a practitioner / patient interaction
- Sharing and the appreciation of the interests of others, which may mean s/he will not seek out information other than the question of immediate concern.

Basic differences in receptive and expressive communication

(Page 4/21)

The [diagnostic criteria](#) (Topic 4 section A) for qualitative impairments in communication highlight the very different ways in which the patient may use communication with the practitioner.

- Delay in or lack of *spoken language* and other forms of communication, may mean that s/he does not readily use speech or written language to communicate so the practitioner will need an 'interpreter' (parent or carer).
- For those with speech, difficulty in holding a conversation – lack of appropriate gesture and intonation as well as the timing and relevance of the dialogue, may make it hard for practitioners to discern what is being said. Use of learned set phrases to answer questions may, in fact be misleading.

Basic differences in receptive and expressive communication

(Page 5/21)

The patient may not see the need to communicate, be hindered by a lack of a suitable topic to communicate and not have a developed system of recognisable communication. Patients with ASD may also not understand that they need to communicate to make their needs known (even able people with ASD may not realise that others do not automatically know what they themselves know or feel or want).

- Stereotyped, repetitive or idiosyncratic language, including immediate or delayed echolalia may

mean that what is said is hard to unravel, particularly if it contains references to apparently irrelevant situations (eg Disney cartoons, Thomas the Tank Engine)

- Development of language may have been delayed or atypical. Patients with ASD are often late to talk (or may not talk) have unusual speech patterns or a pedantic style. Even those with normally good speech may lose the capacity when under high stress.
- If the patient has told his/her symptoms to one practitioner, (or even if they have told no-one) s/he may assume that everyone else already knows what is wrong.

Basic differences in receptive and expressive communication

(Page 6/21)

The young infant with or without a confirmed diagnosis of ASD may present with some very clear indicators of communication and social interaction impairments. There are number of 'alerting signals' in the research that have been detected in very small children.

- Lack of joint attention and shared interest may mean that the child pays little visual attention to social aspects of his/her surroundings and the practitioner; they may not spontaneously follow a finger or eye point to direct their own attention.
- Typical engagement strategies with young children do not always work with patients with ASD
- Failure to turn towards his/her name may mean that the patient with ASD is not aware of being spoken to, nor perhaps even of the existence of the practitioner. Practitioners need to establish the learnt cue for gaining the patient's attention and then remember to use this cue.
- Limited or ineffective communication with others may mean no direct eye contact, preoccupation with an inanimate object, and a lack of an observable relationship with his/her carer

Basic differences in the young infant

(Page 7/21)

The CHAT screening tool (revised [Baird et al, 2000](#)) can be used to explore the particular features of differences in communication.

- Facial expression may appear immobile and it may be difficult to discern emotion. This can make it as hard for practitioners to gauge the emotion of people with ASD.
- There is limited use of gesture and facial expression and absence of appropriate pointing to engage attention. There is an absence of shared attention.

Communication - Adults

(Page 8/21)

A difficulty in the area of communication is a fundamental part of the triad of impairments. Therefore, no matter how articulate an adult with an ASD may appear to be, practitioners should assume that the patient will struggle with some aspects of the consultation and take this into account in their approach.

Conversely, an adult with an ASD may appear to have little or no communication. This is not necessarily the case and a patient who appears to be paying no attention may in fact be listening carefully.

The balance that needs to be achieved is to respect the patient as an adult and communicate directly

with them, but to do so in a way that is not tokenistic, but has meaning for that individual.

Whatever level of understanding the patient appears to have, :

- Seek guidance from parents/carers where possible to identify the types of communication that will work best for that patient
- Address the patient directly
- Do not assume either that the patient does, or does not, understand, based on his/her behaviour alone
- Give information in simple explicit language
- Allow enough time (20-30 seconds) for the patient to absorb information and respond
- It may be useful to provide written notes of key points for the patient to reflect on later or for others to go through with him/her.

Strategies for communicating with the patient

(Page 9/21)

The patient who has no use of language

It is unlikely that a patient with no language will be present at a clinic without some kind of support. The carer accompanying the patient will be able to guide practitioners in how they need to respond to the patient. It is possible that the patient with no spoken language will have another means of communication (Makaton sign language, British Sign Language and the Picture Exchange Communication System are commonly used). It would be helpful to question the parent/carer before seeing the patient.

- Discuss with the parent/carer the preferred means of communication
- Use any spoken means of communication sparingly – keep it short and simple, using key words
- Show any instruments or equipment that are intended to be used to the patient first and demonstrate what is going to happen
- Allow the patient plenty of time (at least double the usual amount of response time) to respond to you
- Check with the carer that your communication is effective
- Non-compliance may mean a lack of understanding

Strategies for communicating with the patient

(Page 10/21)

The patient who has little use of language

The patient with an ASD may be attending a clinic independently if s/he has a basic command of language. However his/her presentation may consist of using basic words and learned phrases to describe his/her reason for the consultation. Such patients may need to show (using gestures or visual aids) why they have come to the clinic. The patient may bring a parent/carer with him/her and this may be the route through the diagnostic/treatment process as above.

For the patient attending independently

- Allow him/her time to express his/her reason
- Check with him/her that the practitioner has understood correctly
- Use a similar level of communication to explain what is going to happen, using visual prompts and key words
- Where the practitioner cannot accurately discern what the patient expresses, then make

enquiries about who could accompany him/her to his/her next appointment as a carer

For the patient attending with a carer.

- Enable the patient to express his/her reason
- Check with him/her and his/her carer that you have understood correctly
- Proceed with low language demands and visual prompts, as above

Strategies for communicating with the patient

(Page 11/21)

The patient who has a good command of language but uses it idiosyncratically

Patients may be able to attend the clinic independently and express their reasons for attending. In the course of the dialogue, however, strange words and sayings may pepper the patients' expression or they may need to go over information already given several times. Their responses may be difficult to anticipate and seem stilted and limited. They may take what is said in a very literal way and respond accordingly.

- Use unambiguous language with no figures of speech
- Avoid using closed questions that only require a Yes or No answer unless necessary
- Relay your understanding of what s/he has said back to the patient
- Clarify his/her reasons for consultation with the patient
- Make sure that any procedure/treatment is fully explained to the patient beforehand
- They need to have an opportunity to ask questions

Strategies for communicating with the patient

(Page 12/21)

The patient who has a good command of speech but less comprehension

The development of expression and comprehension in ASD often does not follow typical development. Patients with ASD may first express themselves without fully comprehending what they, or others, are saying. Thus it is not uncommon to find a patient who can use speech very well but has difficulties with the comprehension of what is said to him/her, especially if it is spoken quickly, with no time to absorb. This can be compounded by literality and poor or limited use of social conventions.

- Make sure the patient has understood what has been said (particular in relation to the illness, symptoms or treatment).
- Find a way to get him/her to demonstrate their understanding.
- Build in checks for each stage of the consultation/treatment to ensure full comprehension
- Avoid figures of speech, long instructions and ambiguous phrases
- Be direct and succinct

Strategies for communicating with the patient

(Page 13/21)

The patient who appears to express and understand well, but follow up reveals inconsistencies

This patient may be the most confusing to deal with. Following the guidance given, it might be assumed that s/he has understood what has been said perfectly well. The hidden lack of communicative competence may have significant consequences, particularly if the treatment has involved his/her independent administration of medication.

Routine medical procedures

- Ensure that the patient has fully understood directions
- Ask him/her to demonstrate what s/he has understood

For medication to be taken independently

- Build in an interim appointment to make sure that s/he is complying with the instructions
- Give written contact details for information if s/he is unsure
- Ensure any script has unambiguous information and simple labelling of medication
- May need daily medication dispenser (giving times)

Using other means of communicating

(Page 14/21)

Objects of reference

This is a system where key objects and events are referenced through generalised objects related to the object or event (e.g. a drink, or wanting a drink is signalled by bringing a standard 'cup' to mean 'I want a drink', keys mean 'We are going out' or "I want to go out").

Ways to use objects of reference

The simplest strategy involves showing the patient the instrument or equipment you intend to use and having an object that resembles some aspect of this, to refer to this equipment.

Using other means of communicating

(Page 15/21)

Pictures/ Photos

This involves the same principle as an object of reference but is a development of that strategy. Real photos or pictures are used to represent the object, event or situation.

Ways to use photographs

- Have a digital camera in the clinic
- Use the digital camera to build up a bank of commonly used equipment and procedures
- Take photographs of all of the rooms in the surgery
- Take photographs of all health professionals
- These images can be laminated and mounted on card to be stored in each area and/or these images can be downloaded onto the computer hard drive as a 'gallery' for use with patients
- Such pictures can also be used in picture sequences to help the patient with ASD understand what is going to happen and in what order

Using other means of communicating

(Page 16/21)

Symbolic systems -Makaton/ Rebus/ PECS

Makaton and PECS, are two popular systems for communicating with patients who have little functional language. Both rely on symbols on cards, computer screen or in a communication book that enable the patient to communicate and for the practitioner to communicate with him/her.

Ways to use symbolic systems

- Check with a parent/carer which system the patient with an ASD uses
- Ask the parent/carer to 'translate' your requests into symbol format
- Enable the patient to communicate with practitioners via this system
- Both systems have clear instructions for use, Practitioners need to take time to familiarise themselves with the system.

Related websites

<http://www.makaton.org/>

<http://www.sensorysoftware.com/resources/Grid%20Sets.pdf>

Using other means of communicating

(Page 17/21)

The Picture exchange Communication system

The Picture Exchange Communication System ([PECS, Bondy and Frost, 1994](#)) relies on cards containing line drawn symbols to be used by the patient to express his/her wishes. PECS is usually stored in an A5 folder where all of the symbols the patient knows are stored

Ways to use PECS

- Make sure with a carer that the patient has his/her PECS with him/her
- Ask the carer to 'translate' your requests into symbol format
- Enable the patient to communicate with you via this system
- PECS has clear instructions for use, the practitioner needs to take time to familiarise him/herself with the system.

Website

<http://www.pecs.org.uk/shop/asp/prodtype.asp?prodtype=7>

Encouraging communication

(Page 18/21)

Four common communicative responses from patients with an ASD will be looked at with strategies for assisting the practitioner: -

Comprehension

Inability to deal with long instructions

Strategies to try

- Use key words
- Deal with one idea per sentence
- Frequently check on comprehension frequently
- Use visual means or written information to back up instructions

Encouraging communication

(Page 19/21)

Comprehension

Echoed response

Strategies to try

- Use a concrete means of showing whose turn it is to speak (eg person holding pen speaks, then hands it to other person)
- Make sure patient has received some item s/he can refer to later

Encouraging communication

(Page 20/21)

Expression

Pedantic delivery

Strategies to try

- Ask patient to give information in short sentences
- Agree on a signal where you can interrupt and ask questions
- Ask patient to pause/stop
- Reassure patients who repeat information that you have understood and do not need a repetition

Encouraging communication

(Page 21/21)

Expression

Poor conversational skills

Strategies to try

- Enable patient to contribute by asking open questions (eg how does this feel....)
- Ask patient to show rather than tell
- Use turn taking idea using an object to show whose turn it is to talk
- Patient may prefer to draw or write down information.

Topic Three : Health Issues

A: Daily living and relationships

B: Emotional issues and mood disorders

C: Idiosyncratic reactions to illness

A: Daily living and relationships

Daily life skills: dressing, toileting, independent management of needs

(Page 2/19)

Dressing:

People with ASD may have problems in organising themselves and clumsiness (even dyspraxia) in some cases. These factors impact on the ability of the person, for example, to dress themselves independently.

Sensory issues affect the type of clothing that can be tolerated.

The fact that these problems may co-exist with high levels of intelligence can puzzle parents and lead to problems at school.

Practitioners need to help carers understand that:

- difficulties in organising themselves are part of the condition and not 'laziness' or a deliberate lack of concentration.
- they can help the child develop independent dressing by using visual organisation strategies (see [Peeters, 1997](#), and [TEACCH](#))
- stripping or refusal to wear shoes results from sensory difficulties, not deliberate naughtiness. Chasing a child to try to force the issue will make things worse by encouraging the child to play 'chase', or become distressed, rather than comply.
- The child (or adult) can be helped by making clothes and shoes as comfortable as possible (eg no zips, buttons, laces, labels) and by gradually desensitising to these for limited periods.

Daily life skills: dressing, toileting, independent management of needs

(Page 3/19)

Toileting and Continence:

Children (and some adults) may present with particular problems in toileting, constipation and incontinence

- Practitioners need to understand the bases of these problems to assist carers and others in dealing with them.
- For the child who has not yet acquired continence skills, carers need to be helped to use a systematic training programme. (see [Azrin & Foxx, 1981](#)) Delays may arise through general developmental delays or because of sensory problems in being aware of signals of a full

bladder.

- Once a child has acquired continence, later incontinent episodes may arise from the inability of people with ASD to become aware of a bodily sensation, while attending to a focus of interest. This is not a developmental problem but it may be appropriate to prompt the individual to attend the toilet.

Daily life skills: dressing, toileting, independent management of needs

(Page 4/19)

Toileting and Continence

Problems with constipation or diarrhoea may lead to further distressing problems of smearing or even eating faeces, because the child begins to fiddle with that area.

Individuals with ASD may develop problems such as constipation from a number of sources:

- There may be problems with the digestive system, including the effects of stress
- The diet may lack appropriate fibre and nutritional balance
- There may be sensory issues that interfere with the willingness to defecate
- Bullying may take place in toilet areas at school when female support staff are not present
- Existing constipation may mean that defecating is painful
- Secondary behavioural problems may arise from any of the above
- Smearing and eating of faeces needs to be tackled by preventing access (supervision on the toilet and the use of a 'catsuit' worn back to front) and giving the individual alternative competing activities (eg having an interesting toy to hold and twiddle when on the toilet).
- Diet needs to be addressed (see below) to keep faeces soft and help maintain regularity. Chronic constipation may need treatment with appropriate laxatives if diet cannot be adjusted.
- Many individuals suffer from chronic and severe constipation or alternatively diarrhoea, due to a poor diet, or possible problems with their digestive systems. Sometimes 'leakage' past severe constipation is treated as diarrhoea and the situation exacerbated.
- There may also be problems in using smelly and messy toilets in school or in public and this can lead to 'holding onto' faeces. There may be other problems related to fear of the toilet bowl, the sound of the flush, the smell of the faeces or just the experience of 'letting go'.

Daily life skills: dressing, toileting, independent management of needs

(Page 5/19)

Independence

Parents/ carers may ask for assistance with problems arising in the area of independence.

Many children with ASD appear prematurely independent because they will help themselves rather than ask (e.g food/drink).

Others develop a form of 'learned helplessness' where they learn to do less and less for themselves, requiring increasing levels of physical and verbal prompting to get them motivated. This may happen in the home where pressure to get ready in time results in parents doing increasingly more for their child just to get them dressed or fed. It may also happen at school, especially where a teaching assistant is assigned to 'support' the child on a 1 to 1 basis.

- Practitioners need to help parents/ carers strike a balance between engineering situations where the child needs to communicate and allowing the child to complete tasks independently without 'nagging' (verbal or physical prompts).
- Parents/ carers need to create situations where the child needs to communicate to get something s/he needs – providing they ensure the child has a system of communication s/he knows how to use
- Children with ASD can be helped to develop greater independence and less prompt dependence through programmes such as [TEACCH](#) where there is specific training for independent functioning; the secret is to have clearly defined and structured tasks followed (and marked on a schedule) by the child's chosen activity. This can be used to train table manners, domestic tasks, washing, teeth cleaning as well as many academic tasks ([Peeters, 1997](#)).

Sleeping Issues

(Page 6/19)

Children with ASD commonly have problems with sleeping and these problems often remain into adulthood.

As children, there are problems in getting to sleep, in sleeping in their own bed, in staying asleep and in waking early. This results in very little sleep for the child, and consequently in very little sleep for the family.

As adults, people with ASD frequently have problems sleeping as well. They often exist on very little sleep (only 2 to 4 hours a night for some children and adults with ASD) but seem at the same time to be suffering from the symptoms of chronic sleep deprivation – adding to their problems of stress.

- There are general guides than can help with establishing good bedtime routines ([Durand, 1998](#)). Since it is often very difficult to alter the amount of sleep the child with ASD has, it may help the family to re-define the problem as not '*How can we get Johnny to sleep longer?*' but as '*How can we get Johnny to be safe and quiet so the rest of the family can sleep?*' The problem then becomes solvable by training Johnny to stay quietly in his room (even in his bed) and listen to music through earphones or to do some colouring-in of patterns.
- Some adults and children with ASD are using melatonin to change sleep patterns. There has been little systematic research ([Hayashi, 2000](#)) but reports suggest that it can be helpful in getting the individual to sleep, but that it does not increase the total amount of time spent sleeping ([Dodge & Wilson, 2001](#)). Parents generally report paradoxical reactions to more traditional sleeping medication (hypnotics), which sometimes cause increased hyperactivity.

Sleeping Issues

(Page 7/19)

Bedtime routines

Often the problem is one of staying in their own bed, rather than with sleep itself

- Parents/ carers need help in establishing bedtime routines that assist the individual in getting to sleep. This is likely to include a period of active exercise followed by a routine of bath, bed and a bedtime story and then bed in a room with little alternative stimulation.
- Aromatherapy or yoga techniques can be used to assist relaxation. Relaxing oils such as lavender can be used to assist, although there is no evidence of effectiveness.
- Where a child is still sleeping with the parents, and this is a problem for them, a behavioural

programme of graded change has been shown to be effective ([Howlin & Rutter, 1987](#)).

Food Fads And Dietary Intervention

(Page 8/19)

Many children with ASD eat very restrictive diets, although most seem to thrive. However, there are extreme cases where diets are extremely restrictive, to the point of risking health.

There are individual preferences for types of food, ranging from totally bland, to highly spiced, and some children

- Even though the restricted diets of children (and some adults) with ASD may not be a health hazard, it adds to the stress of families, and food intake can become more restrictive over time.
- At puberty there is an increased risk of anorexia nervosa in those with AS or HFA. It is thought that the need to be in control leads to these dietary problems. Therefore, approaches to build self-esteem and give opportunities for control in other areas of their lives may help. For young children and those with additional learning difficulties, techniques based on TEACCH structures may be the most promising (see [Jordan, 2001](#)).
- Probiotic foods (e.g. live yoghurts) may help improve gut function by altering the balance of bacteria in the gut of individuals taking a poor diet.

Food Fads And Dietary Intervention

(Page 9/19)

Texture is the main factor in whether or not food is acceptable, especially foodstuffs with combined textures (for instance, a mixture of wet and dry foods).

- When trying to determine the reasons for food fads it is worth considering whether it is the combination of different textures that is the problem (eg having to accommodate to a strawberry in the middle of a yoghurt) and the individual may be prepared to eat the constituents, if these are presented separately (e.g. strawberries and smooth yoghurt).

Food Fads And Dietary Intervention

(Page 10/19)

Diets and environmental causes for ASD

There are as yet scientifically unproven theories about the aetiology of ASD that proposes there are digestive problems leading to insufficient breakdown of proteins, so that peptides and other substances are over-produced, and (possibly because of a damaged gut wall) are absorbed into the blood stream, cross the blood/brain barrier and then interfere with brain neurochemicals ([Alcorn et al., 2004](#)).

- There are gluten and casein free diets which in theory may reduce such problems but studies to date have not provided firm evidence on the benefits of these exclusion diets, although they continue to be popular with some parents.
- There is also a research study under way looking at the effects of a diet rich in omega oils

Sexual Behaviour

(Page 11/19)

Genetic counselling

ASD impacts on the development of social and sexual behaviour, including the implications for relationships, child-rearing, sexual behaviour and genetic counselling for the individual with an ASD and his/her family.

ASD are disorders with a strongly genetic component; it is likely that there are between 3 and 20 genes involved, and there may be a role for environmental factors also in some cases.

There are many research projects being undertaken on the genetic basis for ASD, and some sites on chromosomes have been implicated in more than one study. However, all but 3 chromosomes have been implicated in different studies so there is still a long way to go in identifying the specific genes involved.

- Parents need the opportunity to discuss genetic issues, even if no genes are yet definitively associated with ASD, because they need to understand the risks for their own family planning and to discuss with brothers and sisters of children with ASD
- While the actual genes involved remain uncertain, genetic counselling is based on twin study estimates. The existence of one child within the family increases the risk of having another and there is an even greater risk that other family members will share the 'broader autism phenotype'. (milder variants that are akin to autism but not sufficiently alike to meet the ASD criteria).

Sexual Behaviour

(Page 12/19)

Relationships & sexual development

Understanding social interaction and making relationships is a core difficulty in ASD.

Some individuals manage to relate to one other person but get into difficulties when required to do so with two or more people at one time.

Individuals with ASD vary widely in their interest in others and their willingness to join in social activities.

- Young children with ASD usually find it easier to relate to adults than to others their own age.
- Some problems with groups appear to stem from difficulty in switching and sharing attention. Thus, it is often better to discuss health matters separately with the adult with ASD and his/her carer than trying to do it in a threesome.
- Friendships are best developed around activities where there is a mutual interest and with one other person (although different 'friends' may be involved with different activities). Giving children with ASD positive experiences with others increases their motivation for developing friends and their skill in handling the relationship.

Sexual Behaviour

(Page 13/19)

Developing Relationships

Many students with ASD suffer bullying from peers at school and this can lead to low self esteem and depression as well as school phobia.

Desire for friends may be acute, especially among the most able group with ASD Parent/ carers may seek help from practitioners in developing friendships for the child or young person with ASD.

- There are special programmes for encouraging positive peer interactions now, which may be available from school or voluntary groups
- Perception of being bullied may be accurate, but children with ASD often mistake teasing for bullying and may need reassurance (and sometimes training in telling the difference) and a way of joining in with others.
- If a young person seeks help to obtain a friend, it is first necessary to try to uncover his/her perception of a 'friend'. Young children with ASD may invite 'friends' to tea but then leave them for their mother to entertain while they play on their computer alone. Referral to any local playgroups or creating a 'circle of friends' (Bozic et al., 2002), where there is adult guidance, may help with this.

Sexual Behaviour

(Page 14/19)

Misunderstandings

Difficulties in understanding relationships can lead to misunderstandings and problems.

Adults with ASD who have failed to develop friendships may be helped to have positive experiences with others, develop friends and have a better quality of life if they are able to take part in organised social events. These may be with others with ASD or with the general population. Hatton (2002) describes the success of an adult version of 'circles of friends' that has been established to help with this.

- Older individuals with ASD may regard someone who is kind (or sometimes just polite) to them as a 'friend' or even a 'girl/boy friend'. This in turn may lead to inappropriate overtures by the person with ASD or, in extreme cases, 'stalking' of the individual.
- People with ASD may also be exploited and are vulnerable to abuse by others because of their desire for a 'friend' at any price.
- Men with ASD may in turn be misunderstood when they try to develop relationships with children. They may have unhealthy sexual interests but it is more likely that their interest is 'innocent' and they just do not know how to interact at an appropriate level for their age.
- Practitioners need to be alert to these misunderstandings and consult with parents/ carers to establish the reality of relationships. As with the typically developing, sex education is best within the context of ongoing education about relationships.

Sexual Behaviour

(Page 15/19)

Developing pair bonds & sexual interests

Sexual feelings at puberty may lead to a positive interest in others (sometimes for the first time) and this motivation can be built upon, to increase social skills and develop friendships.

However, problems may also arise around puberty or later when sex education may be misunderstood or when a sexual interest becomes obsessional. Sometimes this can be an obsession with a person but it is more likely (especially among the less able) to be an object ([Haracopus & Pedersen, 1987](#)).

- Difficulty in forming relationships (and sometimes lack of opportunity to do so) may mean that masturbation becomes the only outlet for sexual feelings. This may be a normal healthy solution for the person with ASD and many successful individuals with ASD manage their life very successfully without involving sexual relationships with others ([Grandin, 1986](#)).
- For a few, however (and it is the problems that are liable to be brought to practitioners by parents/ carers or the individuals themselves), masturbation may become a problem in that it overrides other interests and activities and may be indulged in inappropriately.
- Masturbation may be a response to boredom so distraction and enjoyable occupation is always worth trying, although people with ASD are understandably assertive of their rights to experience sexual pleasure ([Pukki, 2003](#)), whether or not this is in the context of a relationship.

Sexual Behaviour

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Masturbation

This can be a satisfactory alternative to a relationship, as long as the person with an ASD knows how to achieve orgasm in this way, and parents/ carers do not have religious taboos. As with personal care, the person needs to be taught where and when it is appropriate to engage in this activity.

Where there is a need for masturbation, it is important that the individual is given clear visual instructions (as with the teaching of all skills), including the need for privacy and hygiene. There are teaching aides available for those with learning difficulties ([Mortlock, 1993](#)).

Some individuals with ASD will follow a religion or have been brought up with certain ethical and moral standards of behaviour and there needs to be sensitivity to these when 'rights' to a sexual life are being explained.

- A visually structured schedule for effective masturbation among less able individuals with ASD, has been produced in Northern Spain and may soon be more widely available.
- The same notions of privacy and modesty should apply here as in the teaching of other self-care issues.
- However, sexual activity is more surrounded with social and cultural taboos than other daily activities and people with autism need to understand about their 'right' to enjoy a full and active sex life but also to understand that others have their own rights. They need to know what is acceptable and unacceptable both legally and socially within the social contexts in which they are situated.
- They need experience of situations when they enjoy positive experiences with others but also support to deal with times when their overtures are rejected. They need to understand this as a fact of life and not to be blamed necessarily on them or their autism.

Sexual Behaviour

(Page 17/19)

Sexual interests

Some sexual behaviour is well within the norm but, as might be expected from their general behaviour, much is idiosyncratic and may not be well tolerated by others.

Problems in reaching climax in masturbation may lead to frustration (and possibly violent and disturbed behaviour) and also continual attempts, which may cause damage to sensitive areas.

There is the significant additional problem of some people with ASD having no sense of shame or embarrassment, which can lead to flamboyant and exhibitionist behaviour. They need social rules for sexual, as any other, encounters.

- Seeking 'fetishes' (objects of sexual interest that facilitate sexual excitement and climax) may lead to dangerous or inappropriate behaviour. Parents/ carers may become aware of this through the frantic search for particular items (see Haracopus & Pedersen (1993) for some examples) that precede masturbation sessions. It may be best to pre-empt the search by providing the desired object, where acceptable, in a safe and delineated environment.
- Sexual frustration may also make the person vulnerable to exploitation and s/he may agree to sex without informed consent, without protection and often at risk of damage. Sex education should include assertiveness training and the understanding that sex is meant to be mutually enjoyable, not painful (Pukki, 2003). Contraceptive advice should include some discussion to try to establish their understanding of, and attitude towards, sex.

Sexual Behaviour

(Page 18/19)

Marriage & long-term relationships

Some more able individuals with ASD do form long-lasting relationships with partners and may marry and have children.

Books, such as those of Aston, based on her counselling experience with couples where one or both partners have Asperger syndrome, are beginning to deal with sexual and relationship problems in a direct and helpful way.

- Autobiographical (e.g. Lawson, 2005; Slater-Walker & Slater-Walker, 2003) and research-based professional (e.g. Aston, 2003) accounts of marriage and gay relationships in people with ASD show that such partnerships may be mutually sustaining, but may also be disastrous (as with the typical population).
- Many problems arise from naiveté and so better education should help. Partnership counselling is beginning to be available for people with ASD.
- There are no research studies on the children from these relationships, but there appears to be a high proportion with ASD, especially where both parents have ASD.

Sexual Behaviour

(Page 19/19)

Sexual frustration

People with ASD may become addicted to Internet sites

Carers may ask for advice about this [Pukki \(2003\)](#) also acknowledges that people with ASD may need help to limit the time they spend on this activity and to understand that this is fantasy and not reality.

There is no research evidence of the dangers of this activity but problems in understanding the difference between fantasy and reality puts people with ASD at risk for misunderstanding and perhaps misapplying what they are viewing.

- Sometimes individuals with ASD spend a lot of time on the Internet visiting violent or pornographic sites. [Pukki \(2003\)](#) suggests this may be helpful and that they should be informed that this is a common occurrence in modern societies for typically developing adults.
- Individuals with ASD may need to discuss (or have pointed out) the fact that the behaviour seen on pornographic sites may be neither typical nor acceptable in real life. This could usefully lead to practical education on what to expect from relationships, how to understand sexual cues, and how to behave in intimate situations. A trusted adult that is not a parent is probably best to deliver this and practitioners may be able to advise on a suitable contact.
- The 'fantasy' nature of pornography should also be stressed.

B: Emotional issues and mood disorders - introduction

Epilepsy

(Page 2/28)

Although the majority of individuals with ASD do not have epilepsy, around 30% do, and a person with ASD is at greater risk of epilepsy if they also have some neurological conditions such as tuberous sclerosis or neurofibromatosis.

There are two peaks for the onset of seizures: infantile spasms (often associated with learning difficulties) and in adolescence.

Epileptic seizures are usually well-controlled in ASD with anticonvulsant medication although this is more true of adolescent onset than infant seizures.

Landau-Kleffner syndrome may be confused with regressive forms of autism because seizures appear (between ages three and seven) in, until then, typically developing children, and these are associated with considerable loss of language. Where there is any doubt a sleep EEG should ensure a differential diagnosis.

Epilepsy

(Page 3/28)

Managing epilepsy and the social and practical consequences may be problematic in ASD, where there may be no awareness of the full consequences of actions. Epilepsy can lead to premature death through status epilepticus or where for example there has been an accident in an unsupervised person near water.

- There may be more risky situations in ASD when the person may not be able to communicate their problems nor understand the basis of social rules (such as do not lock the door of the bathroom when bathing). Parents/carers need support and advice in managing risks and medication, as will the more able adult living independently.
- Safety rules (e.g. letting parent/ carers know you are taking a bath), aimed at preventing tragic consequences of a major seizure, may be forgotten or deliberately avoided because they interfere with other activities (e.g. the person is having a bath at a time when s/he is not supposed to have one, or the person likes to have all doors closed and to lock them against intrusion).
- Diet and sleeping routines, designed to minimise seizures (and work with the medication) may be ignored or forgotten

Anxiety Disorders In ASD

(Page 4/28)

Although it is not a diagnostic feature of ASD, anxiety is almost universal symptom throughout the spectrum

There may be common genetic or brain structural roots (e.g. the role of the amygdala in both conditions) and there are transactional effects throughout development.

Many of the symptoms of high anxiety mirror those of ASD. The effect of anxiety in association with ASD is to make problems worse and even to turn what might be a difference into a disabling disorder. A dual diagnosis may be difficult under existing systems but it is important that the extra effects of the anxiety are recognised and treated.

Anxiety may have direct consequences on health and behaviour:

- leading to an even narrower focus of attention and limiting learning opportunities
- causing high levels of arousal and increasing the likelihood of sensory overload
- making the individual more likely to acquire other anxiety-related disorders
- making it harder to seek or enjoy new experiences and increasing the likelihood of phobic reactions.

Anxiety Disorders In ASD

(Page 5/28)

Types of Anxiety that are particularly associated with ASD are:

- Separation anxiety
- Social phobia
- Social reticence
- Generalized anxiety
- It may appear unusual in a disorder of attachment, but many anxious children with ASD are in fact 'over-attached' in the sense of being fearful about leaving familiar and trusted adults, especially the mother. This can lead to 'clinginess' and a greater reluctance to go to school or go to play with other children
- ASD may itself be regarded as a form of social phobia in many cases so anxiety deepens the fear of others and makes it harder for people with ASD to mix with others and learn from and

with them. It can lead to painful shyness and excessive fear of embarrassment in some of those with Asperger's syndrome.

- People with ASD already find it difficult to make friends and join in with others because they lack the skills to do so, even when they have the motivation. Anxiety exacerbates this and leads to even greater social isolation & fewer peer friendships. They also fear failure.
- Generalized anxiety is perhaps the most debilitating of all. In association with ASD there is often excessive worry about daily events, past and present (e.g. homework, tests, popularity, health) leading to tension, irritability, aches/ pains, or further difficulty sleeping.

Anxiety Disorders In ASD

(Page 6/28)

In many cases, where the anxiety remains untreated in ASD, the person may develop a full-blown anxiety-related disorder.

These severe anxiety disorders are already features of ASD but become both more prevalent and more severe under extreme anxiety.

Severe types of Anxiety Disorder:

- Phobias. These are already prevalent in ASD, being irrational fears brought on by anxiety. Reducing the anxiety through cognitive behaviour therapy (CBT), where possible, may help the person risk exposure to phobic stimuli and thus gain some control and desensitisation.
- Panic- attacks. These arise in ASD when there is anxiety and the person is suddenly exposed to a situation for which they were unprepared. They are often wrongly attributed to 'aggression'.
- OCD. It can be hard to distinguish the obsessions and rituals of ASD with the compulsions of Obsessive Compulsive Disorder (OCD). A rough guide to discriminating the two is whether the person is increasing (as in OCD) or decreasing (as in ASD) their anxiety as they perform the obsession or compulsion.
- Personality Disorder. Asperger described his cases of autism as having a 'personality disorder' and some of the individuals with PDD-NOS might best be described in this way. They would then only be seen as showing the full symptoms of an ASD when they are placed in unsympathetic environments.

Anxiety Disorders In ASD

(Page 7/28)

Managing OCD

Medication may help and newer medications can be very successful in reducing symptoms for some individuals.

However, medication is usually best used as an adjunct to educational and behavioural treatment rather than as the sole treatment

- ASD obsessions are best dealt with by limiting (if necessary), and using them to reward undertaking less favoured activities. It is often counter-productive to try to eliminate them.
- An effective way of managing ASD obsessions is to increase the number (i.e. teach new activities intensely) So that eventually no single activity is itself obsessional.
- OCD obsessions may need forms of cognitive therapy Helping a person overcome an obsessive checking and straightening of objects by teaching him/her to take a digital photo of the straightened object (eg the picture of the doormat) and look at that to resist the temptation to go back and check
- Having a ritual phrase to self-control impulses by saying it aloud

- Having a set number of checks or times that something can be done and sticking to this rigidly

Anxiety Disorders In ASD

(Page 7/28)

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- Having a set number of checks or times that something can be done and sticking to this rigidly

Anxiety Disorders In ASD

(Page 8/28)

OCD may have significant ramifications for other areas of functioning

- An obsession with not wasting food may result in the person eating out of date and hazardous food, as well as overeating
- An obsession with dieting can lead to anorexia nervosa
- An obsession with engaging in a forbidden activity (even one that is just forbidden temporarily) may lead to ignoring other safety rules in the effort to fulfil the activity (eg wanting to observe gables at close quarters may lead to roof climbing)

Anxiety Disorders In ASD

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Wood (2005) has spoken about ASD and anxiety in the following way:

[www.nas.org.uk/content/1/c4/79/04/Saturday Interventions_JeffWood.pdf](http://www.nas.org.uk/content/1/c4/79/04/Saturday%20Interventions_JeffWood.pdf)

The anxiety effects in ASD are often misattributed to the ASD, leading to treatments that do in fact make the anxiety worse for the individual. Misattribution can be of 2 kinds:

Over-attribution to ASD

Assuming ASD is both primary and causal for the anxiety

These can lead to misclassification and mismanagement.

In all cases the ASD has to be recognised as the frame through which to interpret the behaviour but the effects of high anxiety should also be taken into account.

General anxiety and stress reduction techniques will be useful, especially for those of low ability, and Cognitive Behavioural Therapy (CBT) is becoming more used when working with people with Asperger syndrome. It has also been adapted for use with children with ASD (Wood & Dahota, 2005).

Examples of misattribution of anxiety leading to poor treatment:

- A case of high social anxiety treated as a purely ASD child lacking in social skills. Intensity of social skills training that stressed the cognitive deficits i.e. use of Social Stories (without respite of the anxiety) led to increased social anxiety and further problems.
- A perfectionist with high anxiety about making errors and completing work to a standard, was thought to be lazy, unmotivated and to have poor work habits. Increasing 1 to 1 support and prompting, increased his anxiety about his own worth, and dependency on others, exacerbating his problems.
- An extremely anxious school- refuser where this was interpreted as because of poor social skills and problems completing academic work. He was treated by permitting home schooling and reducing work demands, thus reinforcing the sense of his own inadequacy and inability to cope.
- In all the above cases, Wood suggests that treating the anxiety first would have led to a better outcome.

Depression & Bipolar Disorder

(Page 10/28)

There is an established link between ASD and affective disorders such as depression and bi-polar disorder (DeLong & Nohria, 1994). There is probably a genetic link in that families of people with ASD have a higher incidence of these affective disorders than families of other kinds of disorder (i.e. it is not a result of having a family member with a disorder).

There are two sources for depression in ASD:

- *Endogenous depression*: This arises from an independent source from the ASD. As suggested on the left, there may be a genetic root to this kind of depression in ASD. It could be linked to neurochemicals, such as serotonin, which is known to be affected in depression and ASD, and which provides a basis for some treatments.
- *Exogenous depression*: In addition to the biological risks of depression, people with ASD may become depressed through a realistic appraisal of the nature of their difficulties and the curtailment of opportunities that frequently results from ASD. This source of depression appears more common in the more able (or at least is more easily recognised in them) perhaps because they have greater ambitions or are more aware of missed opportunities.

Depression & Bipolar Disorder

(Page 11/28)

Management of depression

- Medication may be necessary but it should be tied in with educational and occupational programmes
- 'Keeping busy' in enjoyable activity is a common antidote to depression for all (including those with ASD) but with the added difficulty in ASD in providing the relevant opportunities
- Exercise is helpful in reducing levels of both stress and depression

Depression & Bipolar Disorder

(Page 12/28)

As with the typically developing, minimising potential environmental causes can help even with

endogenous depression

- Identify SAD (seasonal affective disorder) and ensure adequate exposure to sun light (or to a lamp with the properties of sunlight)
- Reduce stress in the environment by increasing its structure and predictability
- Teach additional coping skills to reduce a sense of impotency

Depression & Bipolar Disorder

(Page 13/28)

Managing depression

Lack of self-esteem and constant rumination over past failures may lead to more depression

- Try to regularise sleep so there are not the chronic effects of sleep deprivation.
- Reduce the level of unstructured stimulation while increasing structured and enjoyable stimulation.
- Produce short term plans (and make these explicit and accessible) with regular 'rewards' in the form of enjoyable activities
- Make programmes (for the child at school or the adult in a work or care placement) that are built on the person's interests and strengths rather than on continual addressing of 'deficits'.
- Where there is sufficient cognitive and linguistic ability, referral for cognitive behavioural therapy (or its equivalent) can help the person put the past in perspective and move on more positively. However this is rarely available in the NHS outside specialized centres.

Depression & Bipolar Disorder

(Page 14/28)

There is an increased risk of bipolar disorder in ASD

The symptoms of bipolar disorder are easily confused with the ASD symptomatology.

- The onset, as among the typically developing, is most common in the teen years
- With hyperactivity and depression both being common in ASD, bipolar may be missed. Practitioners need to be alert to the possibility so they can refer for diagnosis.
- The symptoms associated with ASD are milder and more amenable to change than those associated with bipolar disorder.
- Bipolar manic periods may start at the point that the hyperactivity associated with early childhood in ASD, has diminished
- The depressive episodes in bipolar disorder appear more severe (perhaps in contrast to the manic periods that precede them)

Depression & Bipolar Disorder

(Page 15/28)

Managing bi-polar disorder

- Medication will usually be required, but it should be given alongside education and behavioural approaches.
- Developing specific and explicit visual aids may help the person with the bi-polar disorder understand what is
- happening to him/her and (even more importantly) understand the cyclical nature of the disorder and that each phase will pass.

Self-harm, Suicide Risk and Violence

(Page 16/28)

Individuals with ASD are prone to self-harm.

Self-harm may be a reaction to:

- Anxiety – ‘general non-specific anxiety is hard to bear and self harm may enable people with ASD to focus on this definite sensation instead.
- An unpredictable or overwhelming situation
- A way of triggering endorphin relief (a biological reaction to the injury) and mitigating the effects of the anxiety
- Lack of control – as a way of controlling themselves and the reactions of those around them

Self-harm, Suicide Risk and Violence

(Page 17/28)

In individuals with ASD and additional severe learning difficulties (intellectual impairment), self-harm is likely to arise as a reaction to frustration or panic.

Self-harm may be triggered

- When something unexpected happens and leads to panic
- The adult or child with ASD is confronted (someone invades his/her space) or his/her path is blocked.
- When a well-practised routine is interrupted or blocked
- When the child is unable to have what s/he wants and there is no clear pathway forward
- When something they expected fails to happen.
- When something familiar is changed without warning.

Self-harm, Suicide Risk and Violence

(Page 18/28)

Suicide may be viewed as an extreme form of self-harm but self-harm may also lead to death. Thus, it is triggered by the same kinds of stimuli as self-harm.

In more able children and adults with ASD (as in the general population), suicide may be a reaction to depression (see above).

It may also reflect the value placed on the self and may be a ‘cry for help’ as it often is in individuals who are typically developing.

Practitioners should be alert to factors that would predispose to suicide, with a view to seeking support to prevent the suicide.

Suicide may follow:

- When self harm gets out of control (e.g. the teenager who cuts herself when depressed and inadvertently cuts too deeply)
- When the person is depressed with low self esteem, and cannot see any way ahead
- When the person views his/her future without hope or expectation of something better (e.g.

the young man who reported that 'he could not bear the fact that each day was as hard as the last').

Self-harm, Suicide Risk and Violence

(Page 19/28)

Violence can be seen as the obverse of self harm and will be triggered by many of the same events or situations.

Violence in ASD is often misinterpreted as 'aggression'. This is unlikely where the individual seldom has the understanding of others necessary to show aggression (i.e. they target behaviours not individuals). It is more likely to be a reaction to panic or frustration. Calling it 'aggression' suggests the cause is known whereas describing it as 'violence' makes it easier to see the actual causes and devise more appropriate treatment.

Violence may arise:

- When the person is overwhelmed by sensory information
- When routines are interrupted
- When goals are blocked
- When the individual has no other form of communication or way to get needs met
- When others crowd their space, especially unexpectedly
- When the reactions of others to their violent outbursts are predictable and salient.

Self-harm, Suicide Risk and Violence

(Page 20/28)

Difficulty in becoming aware of their own emotions makes it hard to control their own reactions

- Emotions need to be taught specifically from awareness (through visible external reactions such as increased heart rate, flushing, sweating) of their own emotional reactions to situations
- Once self emotions have been identified they can be taught to recognise the same reactions (and thus emotions) in others
- Identification of their own emotions at an early stage, before it has led to a violent outburst, can help them learn and apply alternative reactions to obtain the same goal.

Self-harm, Suicide Risk and Violence

(Page 21/28)

Medication to control mood disorders may be warranted as part of a programme that also involves behavioural and educational aspects; it should be a short-term measure to help initiate change, although there are individuals with ASD who claim continuing benefit from regular anxiety-reducing medication.

Individuals will vary, so the use of medication should be guided by individual responsiveness – getting feedback from individuals themselves, from parents/carers and from school or day care sources.

- Medication can be used in the early stages of a programme to help the person establish some control of their emotional reactions and gain confidence.
- Long term medication for emotional reactions should be carefully monitored for effectiveness and side-effects.
- Medication when effective alleviates symptoms and treats the underlying condition. It should

be backed up with education to help the person understand the condition and develop new coping skills.

Self-harm, Suicide Risk and Violence

(Page 22/28)

Practitioners need to avoid reactions to violence or self harm that may exacerbate the situation

When faced with an episode of violent or self-harming behaviour that is apparently 'out of control', the practitioner should:

- Work with parents/ carers to isolate the person, as far as is practical, in a safe secure environment
- Offer the person a low chair or clear space on the floor on which to sit. This is a position that will lessen the type and speed of damage and will 'buy' thinking time
- Where the individual is not used to sitting to calm down, try to find a clear (protected from intrusion) space in which they can pace
- Do not analyse or discuss the reaction or the presumed trigger, until the person has calmed down
- Keep at a distance, while observing carefully, to look for opportunities to intervene and possibly distract (e.g. sit in view holding out a favoured item, but not looking at the individual)
- Clear others out of the situation and, if identified, try to eliminate the trigger
- Aim to minimise any potentially harmful effects of these actions.

Self-harm, Suicide Risk and Violence

(Page 23/28)

Reduce extraneous stimulation during outbursts of violence or self harm, although some calming stimulation may be gradually introduced

During the incident:

- Reduce overall stimulation by turning off or dimming major lights (especially fluorescent ones) and any sources of noise
- Observe from a discreet distance – not in the person's personal space
- Low rhythmic humming or gentle singing may be calming – check!
- Reassure the person that s/he will not be allowed to hurt him/herself.

Self-harm, Suicide Risk and Violence

(Page 24/28)

After an incident of violence or self harm there needs to be a period of reflection and an educational plan (for adults as well as children) to try to avoid similar occurrences in the future.

Practitioners need to reflect on the incident and plan their responsiveness to such situations. They also need to consider ways of 'treating' the individual with ASD and responding to the family/ carer needs for training and support.

Following a violent or self-harming incident:

- Staff and parents/ carers need to reflect to identify possible triggers and/or setting conditions that may have led to the problem reaction

- Risk assessment should be undertaken to help with the planning of future appointments
- Staff, parent/ carers and the individual, where possible, need to develop an educational plan for alternative responses to serve the same functions
- Train and rehearse a drill (e.g. sitting on command) that the individual can perform (in response to a definite signal) when s/he is in a panic and not able to think through a problem or put in place a learned strategy.

Forensic Associations With ASD

(Page 25/28)

Any violent incident can escalate so that there could be forensic consequences.

Violence may escalate to dangerous levels because:

- the individual with ASD may have no awareness of the consequences of his behaviour on other people
- the individual with ASD may have no self awareness of his/her actions and thus is not able to control them without external support
- the individual with ASD may have little capacity to reflect on and monitor (and thus control) his/her own actions.

Forensic Associations With ASD

(Page 26/28)

Social naiveté may lead the person with ASD to indulge in activities that are dangerous, socially undesirable or even illegal in pursuit of goals or because they are vulnerable to exploitation by others.

It is not that these offences are more likely in ASD than in the rest of the population but that the person with ASD may commit them in innocence and need education in the social rules.

Desire for a sexual relationship (or even a friend) may lead to following of anyone who displays any sign of friendliness

Desire to belong to a group (or to avoid bullying) may lead the person with an ASD to allow him/herself be set up to engage in dangerous, socially inappropriate and/or illegal activities.

There may be little sense of, or respect for, personal possessions

They may not understand sexual prohibitions and indulge in sexual activities with inappropriate 'partners' (eg children/ animals) or at inappropriate times and in inappropriate (often public) places.

Forensic Associations With ASD

(Page 27/28)

People with ASD may get into trouble because they do not understand the social rules.

They are also more likely to get 'caught' or to admit to a 'crime' because they do not understand these same rules (i.e. they do not know they have done anything wrong) or because they do not lie. They may learn to tell very 'childish' lies to avoid trouble, but most individuals with ASD find it very upsetting to say something that is not real.

Their memory of events is also likely to be very accurate (i.e. it is not distorted by their other views or wishes), although they have difficulty extracting what is relevant from the whole.

Their difficulties need to be taken into account when they appear as victims of crime, but their 'evidence' should not be discounted.

- There may be a failure to generalise social rules to all appropriate circumstances (e.g. they may understand a rule about not 'stealing' from a shop as applying to that shop only)
- When reporting a crime (e.g. when they have apparently been the victims of abuse) the details of what they say can be trusted, but it may need someone who understands ASD to tease out the meaning. They may not understand the intention of others and either miss the abusive nature of the act or interpret necessary care-giving as abusive.

Forensic Associations With ASD

(Page 28/28)

Pursuit of particular obsessional interests may become illegal and/or dangerous in their own right or may cause them to ignore (or fail to register) legal barriers to them indulging in their interests.

- The person with an ASD may trespass to get access to some material or to climb.
- A love of fires and violent outcomes may lead to arson, with no awareness of consequences, beyond the fire itself.

C: Idiosyncratic reactions to illness - introduction

Self Awareness

(Page 2/11)

Individuals with ASD may have difficulty becoming conscious of and reporting their own symptoms.

Many individuals with ASD who are living 'independently' may be at risk of failing to report significant symptoms of illness or injury.

- Bodily sensations may affect behaviour, without conscious awareness.
- Medical causes for challenging behaviour (e.g. ear-ache, tooth-ache, bowel pain) should be checked
- Patients with ASD (even when they have speech) cannot be relied on to report symptoms, or the effects of treatment, especially when attention is elsewhere (e.g. they are engaging in an obsessional activity or they are anxiously scanning a new environment).

Self Awareness

(Page 3/11)

With no understanding of what is, or is not, a serious cause for medical concern, individuals with ASD may become hypochondriacs.

Adults with ASD need training to discriminate symptoms:

- that do or do not require treatment from a medical professional.
- which can safely be ignored and
- which can be dealt with simply through home medication (eg ibuprofen for a headache, or washing and a plaster for a graze).

Self Awareness

(Page 4/11)

They may have unusual and delayed responses to pain or injury and be unable to locate the pain on their body (or be unreliable in doing so).

Individuals with ASD may react very badly to procedures for which they are not prepared, especially if this involves any physical contact.

- Patients with ASD may need to be trained to use a pictorial 'thermometer' to indicate the severity of the pain they are experiencing.
- Unless they have had specific training, they may fail to report significant incidents of bleeding and/or may over-react to benign conditions (eg menstruation, slight bleeding after a superficial graze) and seek medical treatment inappropriately.
- When needing injections, they need to be warned of what is to happen (it will be far more distressing for them to be handled unexpectedly than to be given an injection for which they have been prepared). The cleaning of the area that precedes injection may be far more disturbing to a touch-sensitive patient with ASD, than the injection itself.

Biochemistry And Medication

(Page 5/11)

Individuals with ASD have unusual and even paradoxical reactions to medication ([Gringras, 2000](#)).

- There may be idiosyncratic reactions to medications (as with others) whereby increased doses have a reverse or negative effect. A cautious and watchful approach will be needed.
- As with the general population analgesics such as Paracetamol may be ineffective in some cases ([Alberti et al. 1999](#)), and physicians need to be alert to this possibility, especially where there are problems in reporting reactions to pain.
- Idiosyncratic reactions are to be expected. For example, medication for sleep or to tranquilise may instead lead to hyperactivity and some anaesthetics may be ineffective.

Stress And Anxiety

(Page 6/11)

Stress and anxiety are common, if not universal, features of ASD and both lead to, and react with, illness in ASD.

- The chronic stress associated with ASD leads to stress-related disorders and the individual with ASD will benefit from preventative treatments aimed at stress reduction. These may be discussed with parents/carers.
- The symptoms of any acute illness may lead to additional anxiety and stress because the individual does not understand what is happening and because the symptoms cause changes in appearance and sensation (eg rashes, sore throat).
- Clear explanations (including before and after pictures, for those without good receptive language) of the symptoms and their temporary nature will alleviate some anxiety.

Stress And Anxiety

(Page 7/11)

Effects of stress and anxiety may interfere with the way the consultation is received and understood.

- Visits to a surgery or clinic will cause stress, which can make it harder for the person to take in what is said and may lead to new, or exacerbation of old, symptoms and signs (e.g. further raising blood pressure, dilating pupils and causing sweating).
- Patients with ASD will require even more time than usual (and much more time than others) to make sense of what
- they are told by practitioners in conditions of stress.
- Giving written information to the patient and/or parent/carer will help.

Stress And Anxiety

(Page 8/11)

Stress and anxiety may make it even more likely that the individual with an ASD may not grasp, or may misunderstand, information and advice given in consultations. The Adults with Incapacity Act (Scotland) (2004) makes it difficult to involve others in consultations with adults, unless the person has a severe learning disability. Where this is not formally the case, it may nevertheless be wise to ask the adult with an ASD if they would like to bring a trusted advocate with them to a consultation, especially where important information is to be given.

- A positive response to a question about their understanding may not mean that that is really so, especially under stress, and all verbal information should be backed up by clear unambiguous written (or pictorial, if necessary) information (eg about when and under what conditions to take medication).
- It may be wise to book follow-up consultations to check that medication is being taken appropriately and there are no additional problems.
- Where possible, parents/carers or agreed advocates, should also be given the relevant information, even when the patient is an adult.
- Techniques for cueing patients to take the correct dosage regularly (eg pills packaged by day and time dosage) are needed, even for the most able (most pharmacies will supply a weekly pack).
- Where possible, practitioners should consider 'once daily' dosing.

Social Context

(Page 9/11)

Social signals of all kinds are not salient for most individuals with ASD and the social context is a source of additional stress rather than comfort.

Attention needs to be caught, rather than assumed, and all instructions need to be unambiguous and explicit.

- Where possible, check with parents/ carers about the term to be used to gain attention.
- A person with ASD and additional learning disability, for example, may be used to being addressed by first name only and may not respond when practitioners use more formal or polite modes of address (e.g. 'Mr. Smith', 'sir').
- Do not start talking to the patient (especially if his/her attention is vital) without first using a known signal to gain attention, and giving him/her time to respond.
- Do not begin procedures (e.g. take hold of a wrist to test a pulse) without giving a clear warning and time for preparation.
- Wherever possible give parents/ carers warning of the kinds of procedures and tests to be used so they can help prepare the person (child or adult) for the experience.

Social Context

(Page 10/11)

Misunderstandings may arise from failure to appreciate social assumptions and lead to unusual or distressed behaviour, or failure to comply. People with ASD do not read the intentions of others easily and may confuse necessary or therapeutic touching or handling with assault.

- Do not assume that an instruction such as 'you can get changed now' will be interpreted as an instruction to take off some clothes (or one's own clothes); the instruction needs to be precise and specific.
- Instructions to 'give me your arm' in the context of a clinic or surgery, where the person may believe amputations are possible, may lead to a panic reaction; re-phrase as 'let me hold your arm to take your blood pressure' or whatever is appropriate.

Social Context

(Page 11/11)

It is important to try to reduce the stress of individuals with ASD turning up for appointments by making the setting as 'autism friendly' as possible

- Give an appointment time outside normal surgeries so patient can be seen without waiting.
- Waiting for treatment in a crowded waiting room may lead to intolerable stress and consequent reactive behaviour.
- Make a seat available that is in a comfortable position for the patient (eg at a distance from others and positioned so that others cannot approach from behind) or give a clearly demarcated area in which the person can pace.
- Distraction with something to hold and manipulate can significantly reduce additional stress.
- Do not engage in 'social chit-chat' in an attempt to put the patient at ease. This is likely to have the reverse effect and will confuse and disturb the person with ASD.

Topic Four : Identification and diagnosis

A: Identification and diagnosis

B: Screening and co-occurring conditions

C: What follows diagnosis?

A: Identification and diagnosis - introduction

Diagnostic Criteria For ASD

(Page 2/20)

The diagnostic criteria for all ASDs are grouped into three areas, commonly referred to as the triad of impairments. These are the bases for the criteria in DSM IV and ICD 10.

ASD does not feature as a diagnostic category in either of the international diagnostic systems, but there are criteria for the three disorders of:

- Asperger syndrome
- Autism
- PDD-NOS (pervasive developmental disorder not otherwise specified)

Other subgroups which fall within the autism spectrum are:

- Childhood Disintegrative disorder
- High Functioning Autism
- Semantic Pragmatic Disorder
- Diagnostic criteria

Three areas of the triad are:

1. *Qualitative impairment in social interaction*
2. *Qualitative impairment in communication*
3. *Restricted, repetitive and stereotyped patterns of behaviour, interests and activities*

Diagnosis is made if evidence is found of impairments in all three areas and onset has been apparent prior to the age of 36 months. Atypical autism or PDD-NOS may be diagnosed when absolute criteria for all 3 areas are not met but core social impairment is there. In addition to asking questions in relation to the areas above, it is useful to ask about special skills, interests and abilities.

Each of the three areas will be explained in the next three screens.

Diagnostic Criteria For ASD

(Page 3/20)

Qualitative impairment in social interaction and social understanding

Qualitative impairment in social interaction in at least two of the following areas:

- Use of non-verbal expression on (eg appropriate eye contact; limited facial expression on, body posture and gesture) and the social timing of these
- Difficulties in relationships with peers

- Lack of sharing and enjoyment in others' interests
- Limited social and emotional reciprocity.

Diagnostic Criteria For ASD

(Page 4/20)

Qualitative impairment in communication

Qualitative impairment in communication in at least one of the following areas:

- Delay in or lack of spoken language and communication in other forms
- In those with speech, difficulty in holding a conversation
- Stereotyped, repetitive or idiosyncratic language, including immediate or delayed echolalia
- Lack of pretend play or limited social play

Diagnostic Criteria For ASD

(Page 5/20)

Restricted, repetitive and stereotyped patterns of behaviour, interests and activities

Restricted, repetitive and stereotyped patterns of behaviour, interests and activities, as shown by at least one of the following:

- Preoccupation with one or more interests which is unusual in its intensity or focus
- Rigid adherence to specific routines or rituals
- Stereotyped motor mannerisms (eg hand flapping; finger gazing; complex body movements)
- Persistent preoccupation with parts of objects or machines (such as washing machines; videos)

Causation and onset

(Page 6/20)

Onset of ASD is usually prior to 36 months.

The majority view is that ASD has a genetic and organic basis and cannot be caused by inadequate or negligent parenting.

Those with an ASD have a different neurobiology to those who are typically developing.

This leads to different perception, processing and responses to situations.

Research suggests that early trauma, neglect and abuse does not cause ASD, but may lead to quasi-autism in some, which disappears when conditions become more conducive ([Rutter et al.1999](#)).

The needs of parents

- Despite this evidence, parents are still often blamed for their child's apparent anti-social and difficult behaviour BEFORE diagnosis. This can make them angry and mistrustful of practitioners.
- Parents often see many practitioners and may have received conflicting views and advice on the child's difficulties.
- Practitioners need to explore what the parents have already been told and how they feel about previous consultations.
- Practitioners need to ask parents to give their views on possible reasons for their child's difficulties.

- It is vital to listen to the parents and trust their accounts.

Causation and onset

(Page 7/20)

There is strong evidence for the heritability of ASD and an increased risk that siblings and the parents of children with ASD will also have ASD, or a milder variant.

The needs of parents

- The parents themselves may have difficulty in some aspects of the consultation process (eg attending to what is said; processing rapid spoken information). Giving written back-up information might help.
- A series of short consultations is preferable to a long session because of the problems in retaining information in a stressful situation

Causation and onset

(Page 8/20)

ASD persists into adulthood. It may be harder to detect the condition then, as adults have developed skills and learned strategies to manage or avoid situations they find difficult.

- Taking a detailed history from the adult and/or parent/carer and reading past reports, if available, are vital sources of information in the diagnostic process.

Diagnostic Assessment Process

(Page 9/20)

This varies throughout the UK in terms of who is involved, how the assessment is made and what and when it is offered. To improve consistency and enhance the quality of service, a working group (National Initiative for Autism: Screening and Assessment NIASA) was formed to consider best practice in diagnostic assessment and intervention in ASD. Their report, entitled National Autism Plan for Children (NAPC) (NIASA, 2003) is a key text, primarily for preschool and primary children.

The Scottish Intercollegiate Guidelines Network (SIGN) guideline " Assessment, Diagnosis and Clinical Interventions for Children and Young People with Autism Spectrum Disorders " is due for publication December 2006. This will give guidance on children up to the age of 18 years.

Key recommendations on diagnosis from the NIASA report are as follows:

- All existing information should be obtained across settings and disciplines
- A detailed developmental and family history should be taken by practitioners experienced in ASD.
- The individual should be observed in different, natural settings, including home, if possible.

Diagnostic Assessment Process

(Page 10/20)

ASD affects many areas of development and is classified as a Pervasive Developmental Disorder. To gain a comprehensive profile of the individual with ASD, it is vital to obtain the views of professionals working within and across agencies who know the individual well.

The NIASA report recommends that:

- Reports on current functioning should be obtained from those who know the individual and the family
- An assessment of the needs and strengths of the individual and the family should be made
- In addition to information on the three core areas of ASD, an assessment of unusual sensory responses, motor planning and coordination difficulties and self-care skills is needed.

Diagnostic Assessment Process

(Page 11/20)

Focused observations across settings, should involve observing the individual interacting with others including parent/carer, unfamiliar adults, siblings and peers.

Communication and social interaction need to be assessed in terms of the frequency and type of contact initiated with others and their response to others.

Primary care practitioners may not be involved in full diagnostic assessment but will need to gather related information in order to refer for further investigation, where appropriate.

Situations to observe include:

- Play/leisure activities when the individual is alone
- Nature and frequency of interaction with siblings and peers at home and school/workplace
- Nature and frequency of interaction with parents and familiar adults with and without toys/materials
- Response to structured play/tasks set up specifically for assessment purposes (Autism Diagnostic Observation Schedule ADOS)

Diagnostic Assessment Process

(Page 12/20)

Diagnostic process – medical tests

There are a number of conditions, which appear to be associated with ASD and specific testing or assessment may be required.

NIASA recommends that, as part of a full diagnostic procedure, practitioners routinely carry out chromosomakaryotype and fragile X DNA analysis, assess for the possibility of epilepsy and check their sensory responses and motor coordination.

Primary care practitioners should be aware of these likely investigations and be able to discuss them with parent/carers or the individuals with ASD themselves.

Diagnostic Assessment Process

(Page 13/20)

Diagnosis of adults with ASD

There are many adults with ASD who have not been diagnosed since there was less expertise on ASD when they were children or their skills masked their problems

Some of these adults may not require, or benefit from, an official diagnosis or intervention as they are able to manage their lives without such support.

Others, however, who have a late diagnosed of with ASD have experienced significant problems with daily living, employment and relationships with family and others and often develop mental health disorders (see biographies by Lawson (2003), [Sainsbury](#) (2000) and [Gerland](#) (1997)).

There are a number of reasons why there are currently many adults with ASD who have not yet been diagnosed or who are late diagnosed, as follows:

- Their skills, particularly their spoken language and academic achievements have masked their difficulties.
- When they were children, there were far fewer professionals who had experience in ASD.
- Taking a good and reliable developmental history on an adult may be difficult unless good written records exist or the parent/carer or patient is able to recall early events.
- Other explanations were given for their behaviour or difficulties (eg depression; schizophrenia; agoraphobia, personality disorder).

Diagnostic Assessment Process

(Page 14/20)

Diagnostic Instruments

As yet, there is no biological, medical or psychological test, which can confirm the diagnosis.

Diagnosis is made on the basis of taking a detailed developmental history and observing the individual in a number of different settings (both natural and clinic settings).

Diagnostic instruments have been developed to help practitioners know which questions to ask in relation to the main diagnostic criteria.

Diagnostic instruments designed to obtain a good developmental history include:

- ADI-R: Autism Diagnostic Interview Revised (Lord et al., 1994)
- DISCO: Diagnostic Interview for Social and Communication Disorders (Wing, 2002)
- ASDI: Asperger Syndrome Diagnostic Interview (Gillberg et al., 2001)
- Specific training to use these is required and is restricted to certain professional groups

Diagnostic Assessment Process

(Page 15/20)

Observation of the individual

Diagnostic instruments to help practitioners know what to observe and record have been developed.

Diagnostic instruments which include structured observations to aid diagnosis are:

PL-ADOS: Prelinguistic Autism Diagnostic Observation Schedule ([DiLavore et al., 1995](#))

ADOS: Autism Diagnostic Observation Schedule (Lord et al., 1994).

Benefits And Risks Of Diagnosis

(Page 16/20)

This section covers the potential benefits of diagnosis to the individual and the family, but also explores some of the risks and current issues surrounding diagnosis.

Potential benefits of diagnosis to the individual with an ASD

- Helps individual understand source of own difficulties and identify possible strengths.
- Guides appropriate intervention
- Alerts all professionals involved, to the particular needs of the individual and family
- Gives parent/carers access to specific ASD literature, support groups and other parent/carers
- Helps in decisions about provision
- Gives access to financial allowances
- Enables those who are able to read about ASD and develop an understanding of the difficulties they have.
- Parents/carers not blamed for their child's behaviour and may get support from family and professionals.

Benefits And Risks Of Diagnosis

(Page 17/20)

There are a number of benefits of diagnosis for professionals and parent/carers as well as for the individual concerned.

This screen suggests the benefits for parent/carers of having the diagnosis.

Potential benefits of diagnosis to the parent/carers of individuals with ASD

- Aids understanding of the behaviour of their son/daughter and access to sources of help for difficulties
- Alerts all professionals involved to the particular needs of the individual and family
- Gives parent/carers access to specific ASD literature, support groups and other parent/carers
- Helps in decisions about educational/ living provision and career choice
- May give access to financial allowances to support in daily living, in further and higher education
- May give access to employment support schemes
- May give access to more suitable housing or living provision.

Benefits And Risks Of Diagnosis

(Page 18/20)

There are a number of benefits of diagnosis to the adult with an ASD.

This screen suggests the benefits for the adult with ASD in having the diagnosis.

Potential benefits of diagnosis to the adult with ASD

- It allows the adult to make sense of himself /herself.
- Other people's responses might alter for the better once the diagnosis shared.

- Enables the adult to access the literature and support groups and develop an understanding of ASD and his/her own difficulties and strengths
- Enables the adult to develop strategies to address his/her own problems.
- Gives access to ASD specific Internet sites to access information and to allow discussion with others.
- Self esteem may be enhanced by meeting, reading about and emailing successful people with ASD.

Benefits And Risks Of Diagnosis

(Page 19/20)

Relatively little has been written about sharing the diagnosis with the individual child or adult with ASD.

Jones (2002) has written an article on this largely based on accounts of adults who were late diagnosed.

Individuals with ASD may have little understanding of risk or uncertain outcomes and little tolerance of them.

Sharing the diagnosis with the individual child or adult

Key questions to ask are:

- Is the individual ready for this discussion?
- Are important others (eg siblings; staff; employers) aware of the diagnosis?
- Are his/her peers aware of the diagnosis?
- Who will initiate the discussion of his/her diagnosis?
- What do you think the benefits might be to him/her and to others?
- What are the potential negative consequences of sharing the diagnosis?
- How will you illustrate what ASD means?
- Outcomes that are uncertain, or only applicable to certain individuals or situations, need to be handled sensitively so the person with ASD does not understand 'may' as 'will' or does not think that alternative outcomes listed ALL apply.

Benefits And Risks Of Diagnosis

(Page 20/20)

Some adults with ASD have become depressed on being given their diagnosis. Potential benefits and disadvantages have to be considered.

Potential difficulties experienced when the diagnosis is shared with the individual child or adult

These include:

- Depression, when s/he learns ASD is life-long and so problems may not go away.
- Anger that they have been misdiagnosed or mistreated in the past.
- Sadness that the response of others has not changed.
- Sharing the diagnosis with others has led to teasing or has been challenged.
- These should not be reasons for deciding not to share the diagnosis, but illustrate that this work has to be done sensitively and over time.

B: Screening and co-occurring conditions - introduction

Parents' Concerns

(Page 2/13)

Parents' early concerns have usually been around delayed language; lack of response; deafness; difficulties in engaging and comforting their child

Parents have often spent several months and sometimes years concerned about their child and received conflicting (and often upsetting) messages from professionals.

Listening to parents – important information to collect includes:

- The nature and timing of their first concerns
- Parents' current concerns
- Professionals seen to date and the views they have expressed
- The parents views on the possible reasons for their child's difficulties
- Views of the wider family on the child's difficulties
- Parents' feelings and views on the advice and support they have had to date.

Alerting Signals

(Page 3/13)

A consensus has developed on the early indicators of ASD

Early indicators – alerting signals include:

- No speech or delayed speech
- Unusual response to others
- Lack of joint attention and shared interest
- Difficult to comfort when upset
- Failure to orientate to name
- Limited or ineffective attempts to communicate with others
- Limited use of gesture, often absence of pointing and limited facial expression
- Extreme distress or distressed by unpredictable events

It is important to train all practitioners in the alerting signals for ASD.

Alerting Signals

(Page 4/13)

Age at diagnosis

Some individuals with autism have established features by the age of two years and can be diagnosed by experienced practitioners. The average age at diagnosis varies between authorities/areas and is often much later for those with Asperger syndrome and high functioning autism ([Howlin & Moore, 1997](#)).

Early diagnosis is desirable because:

- Appropriate intervention can start early
- Parents spend less time not knowing the diagnosis
- Other family members can understand and be more supportive
- Parents can give appropriate support at home
- Professionals involved with the child can understand the child and take relevant actions.

Alerting Signals

(Page 5/13)

Identifying able children and adults with ASD

It is harder for able children and adults to obtain a diagnosis as their abilities mask their difficulties and their verbal responses to questions may mislead as a result of the literal interpretation or processing problems ([Howlin & Asgharian, 1999](#)).

They may have high levels of skill in certain areas relative to peers and to their other skills. Self help and organisational skills may be very much lower than one would expect of a typically developing individual.

The term high functioning autism (HFA) can mislead parent/carers and others. The developmental profile in ASD is often much more uneven than in the typically developing person so that one should not assume high levels of skill across all areas.

For the able child or adult with ASD, information on the following areas is useful:

- Nature of conversational skills and topics.
- Social and pragmatic uses of language (including body language; intonation; volume; eye contact).
- Reasons for communication with others.
- Activities pursued in 'free time' - both indoors and outside – with and without others.
- Nature of particular skills or interests.
- History of social interaction and responses.
- Functional level of daily living skills relative intellectual ability; shopping; crossing roads; cooking, personal hygiene

Screening Instruments

(Page 6/13)

There is as yet, no reliable screening test for ASD. Attempts have been made to devise such a test, the most commonly known being the CHAT ([Baron-Cohen et al. 2000](#)).

- The CHAT (Checklist for Autism in Toddlers) comprises nine items completed by parent interview and five items completed from structured observation in the clinic or home for children aged between 18 months and 36 months. It has been used to train primary care workers in the alerting signs for ASDs in some areas.
- A modified and expanded version of the CHAT – the M-CHAT ([Robins et al., 2001](#)) is currently being tested.
- The CAST Childhood Asperger Syndrome Test ([Scott et al., 2002](#)) has recently been developed for use with primary school aged children but requires further evaluation.
- ([NAPC 2003](#)) does not recommend whole population screening for ASD as there is as yet no sufficiently reliable instrument for this.

Subgroups

(Page 7/13)

There has been longstanding debate as to the differences between the subgroups in ASD and this continues (see [Bishop, 1989](#)).

The main subgroups found in the literature on ASD (although not all are in DSM IV and ICD 10) include:

- Asperger syndrome
- High functioning autism
- Autism
- Pervasive Developmental Disorder – Not Otherwise Specified
- Childhood Disintegrative Disorder

In addition, there are those who argue that children with Semantic Pragmatic Disorder also have difficulties throughout the triad of impairments.

Subgroups

(Page 8/13)

Asperger syndrome

The term Asperger syndrome (AS) was introduced by [Wing \(1981\)](#) to the English speaking world, to highlight the needs of able people with autism (based on the work of Asperger with this group) and was viewed as the able end of the autistic spectrum. Since then, some have suggested that those with AS are different in other ways to those with autism.

High functioning autism (HFA) and AS share very similar characteristics and become more similar with age.

The main distinguishing feature among diagnostic categories is that individuals with HFA are delayed in developing speech ([Szatmari, 1998](#)). There is also the suggestion that individuals with HFA had more severe symptomatology in early childhood (although this, too may be a consequence of poorer communicative ability).

The main criteria which distinguish those with Asperger syndrome from other groups within the spectrum are that:

There is no delay in developing language or speech

They do not have general cognitive impairment

Having said that, both children and adults with Asperger syndrome have major problems in social understanding and communication. They may have extensive spoken vocabularies and fluent speech, but be unable to use these effectively in social conversations and in communication with others.

Subgroups

(Page 9/13)

High functioning autism

The term 'high functioning' has been criticised by adults with this diagnosis as it implies they are more able than is actually the case, leading other people to assume they are able to perform tasks, which are beyond their ability. This is particularly so if there is a social element in the task or it involves multi-tasking.

The main distinguishing features between those with AS and HFA are that those with HFA

- May appear to have had cognitive impairment when young
- Meet criteria for autism, whereas those with AS do not
- Are delayed in developing speech. ([Szatmari 1998](#)).

By adulthood, it may be difficult to separate out these two groups.

Differential Diagnosis

(Page 10/13)

Misdiagnosis and over-diagnosis

Differentiating an ASD from other disorders can be complex, where the child has additional disorders or where there has been early childhood trauma.

Many children in the first few years of life experience communication and social difficulties but do not have an ASD.

There are issues in some areas of over-diagnosis of ASD, where practitioners appear to misdiagnose ASD on the basis of other difficulties.

Children who might be incorrectly diagnosed or suspected of having an ASD are:

- those in care or those who have experienced separation and emotional and psychological abuse may appear to have an ASD (but do not); although there will be some in this group who do.
- those with ADHD or emotional and behavioural problems.
- those with other speech and language disorders who may have a similar profile of difficulties in the early years, although they are usually socially more skilled.
- those with delayed development or unusual behaviours.
- those with visual or hearing impairments.

Differential Diagnosis

(Page 11/13)

Misdiagnosis and Missed diagnosis

Adult biographies of those with ASD frequently refer to misdiagnosis (eg [Lawson, 2001](#); [Sainsbury, 2000](#); [Aston, 2000](#)).

Mental health disorders such as schizophrenia or OCD may have been diagnosed incorrectly and antipsychotic medication prescribed, often because of the way in which adults with ASD respond to questions about the mental state and experiences.

These misunderstandings may occur because of the literal use of language, echolalia and the use of the affirmative to shorten the interaction ([Howlin 2003](#)).

The following situations might occur:

- Behaviour may be misinterpreted and may be labelled as naughty, anti-social, lazy, rude or deviant.
- ASD may be missed in children with severe learning difficulties, Downs syndrome, visual, hearing or physical impairment.
- ASD might be missed in children who have had abusive or traumatic early experiences as their social and communication problems are thought to stem from those experiences rather than ASD.
- ASD might be missed in children for whom English is an additional language because of cultural factors.

Co-Morbidity

(Page 12/13)

There is a danger that once ASD has been diagnosed, that this is viewed as the primary cause of behaviours seen and further diagnoses of other conditions may be overlooked.

It is possible for a child to have an ASD together with any other childhood disorder.

Other conditions which can co-occur with ASD and which seem to be more prevalent in ASD than in the typical population are:

- Epilepsy
- General cognitive impairment
- Dyslexia and hyperlexia
- Dyspraxia
- Depression
- Chronic anxiety

Clearly it is also possible for an individual with ASD to have any other condition in addition to ASD, including:

- ADHD
- Cerebral palsy
- Downs syndrome
- Sensory impairment
- Mental health disorders

Co-Morbidity

(Page 13/13)

Mental health issues

Depression and anxiety are likely to be more common in the ASD population due to the nature of their social and communication difficulties, but much can be done to prevent such conditions by providing appropriate and supported environments at home, at school and in employment. ([Ghazuiddin 2005](#))

The difficulty of those with ASD in expressing their feelings and emotions using speech and the

problems in differentiating behaviours due to ASD and those which may underpin anxiety or clinical depression can make diagnosis of mental health disorders difficult.

Practitioners need to check for evidence of mental health disorders, particularly depression, anxiety and OCD

It is important to:

- Involve all who know the individual well in the assessment
- Obtain a history of the behaviours.
- Determine the contribution of the past or current stresses on the condition.
- Select the least restrictive intervention to address the condition.

C: What follows diagnosis? - introduction

Diagnostic Reports

(Page 2/6)

Diagnostic report – terminology

It is advisable to avoid the use of terms such as ‘autistic traits’, ‘autistic features’ and ‘autistic tendencies’ in reports as there is no behaviour or trait, which is of itself unique to ASD.

Diagnosis is based on a particular combination of behaviours, which occur together and to missing aspects of typical development, so the term autistic should not be used unless all the criteria for a diagnosis are met.

- Statement about the nature of the evidence on which the diagnosis was made.
- Comment on the certainty of diagnosis and any contra-indications of ASD.
- A clear explanation of ASD using examples of the individual’s behaviour to illustrate this.
- Information on early development and current functioning.
- Results of test scores with explanation given as to their value.
- Areas of strength and special interests.
- Areas of development, which need intervention, both within the triad and in other areas.
- Advice on how to support the parents and the individual at home and elsewhere.
- References to the literature on ASD.
- Information on local support services.
- Parents’ views on diagnosis and the report.

Sharing The Diagnosis With The Parents

(Page 3/6)

Sharing the diagnosis with the parents is a highly skilled and sensitive task in ASD as in other conditions.

Practice varies across the UK in terms of how this is done and by whom.

This task will not usually be the responsibility of primary health care professionals, although they may be the first to suspect an ASD diagnosis and may be asked to elaborate on issues relating to diagnosis.

Good practice is that where practitioners discuss:

- When to give the diagnosis
- Where to give the diagnosis
- Which family members or friends should be present
- Which person(s) is best to deliver this
- The spoken and written information that will be given
- How and when the first session will be followed up

However, it is NOT good practice to deny access to a diagnosis to the parents/carers or the individual (where appropriate) when that diagnosis has been made. If the diagnosis is uncertain, that uncertainty should also be shared, together with the steps to be taken to help achieve a firm conclusion.

Recommendations On Interventions

(Page 4/6)

The main purpose of diagnosis is to guide decisions on how best to support the child or adult. Recommendations should therefore be suggested at the time of diagnosis and a section included in this within the diagnostic report.

NIASA recommends that intervention should follow within 6 weeks of the diagnosis being given to the family.

Clearly, professionals from health, education, social services and the voluntary sector need to work together to discuss the following:

- Which services need to be involved in making recommendations to support the family?
- To whom should the diagnostic report be sent?
- Would it be useful to appoint a keyworker to coordinate the work, and if so, who should this be?
- Who will check that the recommendations are carried out?

Recommendations On Interventions

(Page 5/6)

There is great variation within the population of those diagnosed with an ASD depending on intellectual ability and the co-occurrence of other conditions. Reviews of research suggest that an individual with ASD will benefit from a number of different services and interventions and that these will differ between individuals and over time.

Not all children or adults will benefit from a particular approach and this is also true for all educational or therapeutic goals.

Those involved with the individual and the family need to make an assessment of what interventions are likely to help develop skills and understandings and which services might deliver these.

To summarise:

- Individuals with ASD differ from each other and so will need different types of intervention.
- Parents and families differ in terms of what they would find useful or what they are able to access or take up.

- A service should therefore be able to offer a range of approaches to both the individual with ASD and the family
- Priority goals for young children should be to enable both child and parents to interact successfully.

Recommendations On Interventions

(Page 6/6)

A consensus is developing from reviews of research on the key elements and goals of successful and effective interventions.

Identifying the key components of programmes and services which seem to be effective is very helpful in evaluating practice and guiding interventions.

It is important to recognise that failure to provide timely and appropriate interventions for children with ASD post diagnosis, leaves parents vulnerable to 'advertisements' for expensive (and often untested) interventions on the Internet.

Key components of interventions which are effective in ASD include:

- Early intervention following diagnosis
- Parental involvement
- Recognising the sensory issues for the individual
- Giving structured and predictable activities and timetables over 24 hours
- Including relaxation opportunities
- Having clear communication systems for all
- A functional approach to behaviour and the teaching of acceptable alternatives
- Those which support transitions
- Physical exercise (aerobic)
- Those which highlight the strengths and interests of the individual
- Those where staff and parents discuss and monitor the effects of intervention.

Scenarios

Natasha

Natasha is a fourteen year-old girl, diagnosed with severe autism and has speech consisting of single words and set phrases.

She is able to communicate basic needs through words, symbols and signing. She is excessively attached to her mother, from whom she will demand a lot of individual attention and who serves as a model for many of her behaviours, including close imitation of the way she sits on chairs, drinks her coffee and so on. When with her mother she will continually demand attention with forceful gestures (e.g. turning her mother's face to make her look at her, using 'demand' utterances).

Natasha's mother has tolerated this behaviour, although it makes her tense and she suffers from severe tension headaches.

Natasha has been trained at home to leave her mother alone at these times and is given the explanation that her mother's head is hurting and she has a 'headache'. Sometimes, when Natasha appears irritable and behaves 'badly' at home, her mother uses this as a possible 'explanation' of Natasha's behaviour as well. Thus she asks her what the matter is, and then (when Natasha does not respond) supplies the answer "Perhaps you have a headache? Does your head hurt?". Natasha has learnt to say "Yes" to this, since it produces undivided loving concern from her mother.

However, an unwanted consequence of this pattern arose recently, when Natasha went away on a week's holiday with the staff of the specialist day school which she attends. After 2 days away, she began to show signs of being very unwell. She had been irritable for a day before and had not been eating properly (unusually, as she has a large appetite normally, at least for favoured food). Staff wondered if she was home-sick and missing her mother, but on the 3rd day she vomited her meal, had an elevated temperature and was hitting herself and others in clear signs of distress. A relatively inexperienced member of staff asked her what was wrong. Natasha answered with apparent clarity and conviction that she had a headache. The staff member did check, by asking Natasha to show her where it hurt. Natasha pointed to her head, which satisfied the member of staff who went to a senior member of staff to give her ibuprofen (as she was not able to tolerate paracetamol).

The senior member of staff was more aware of Natasha's history with her mother and of the unreliability of cued responses to questions. In the light of the vomiting, continual raised temperature and obvious signs of acute distress, Natasha was taken to hospital. There it was discovered she had acute appendicitis which would have proved fatal had it been left longer.

Simon

Note: This was also the basis of a case study reported in a book, now out of print: (Kiernan, CC, Jordan, RR. & Saunders, CA. (1978) Starting Off London, Souvenir Press)

Simon was a 7 year-old boy with severe autism and profound learning difficulties. He could walk and run but was mute and doubly incontinent. He had an extremely limited repertoire of behaviours, mostly consisting of tapping and twirling but he also enjoyed peering through lines and twiddling sparkling and brightly coloured objects. He relied on routines and would scream uncontrollably for hours if his routines were disturbed in any way or when he was presented with new situations.

Simon had proved impossible for his mother to wean and he had never eaten solid food. His mother

had made several attempts but he would resist and gag at anything other than liquid, which he had to have from the same bottle with the same teat (or a new one boiled until it reached the same consistency as the old one). He existed on a liquid food supplement but he was extremely frail and it was felt that his future health was uncertain. It was a priority to move him onto a solid diet.

After some false starts, a behavioural method was used, with professional support to the nursery nurse designated to carry out the programme. Simon was to retain his liquid supplement in a bottle at the usual times to ensure he had some nutrition and parental anxiety (previous attempts to interfere with his bottle time had led to Simon completely reject all food, including the bottle, and ending up hospitalised and being drip fed for several days). At two other totally different times of the day, he was taken to a different setting and offered food. To begin with he just had to tolerate a spoonful of ice-cream touching his tongue for him to be allowed to play for 3 minutes with a large box in which all manner of delights had been placed (Christmas tree lights, grills from the oven etc.). After 3 minutes of play, Simon was returned to the nursery nurse and offered another spoonful.

Initial extreme resistance rapidly dissipated and in four month's time Simon was eating a bowl of ice cream before being allowed to play with his objects. It took a further 3 months to get him to tolerate ice-cream mixed with custard, then savoury smooth soups, then mashed potatoes, then some lumps. It took two years of a slow step at a time programme for Simon to be eating a reasonably varied diet of solid foods.

Sam

Sam was late being diagnosed with Asperger syndrome. His mother had been aware of his difficulties since he was aged two years. Despite repeated visits to professionals to express her concerns, this diagnosis was not suggested as an explanation of his difficulties.

During his years at primary school, his mother was frequently called in by teachers who complained about his anti-social behaviour. She used to dread going to the school to collect him. The teachers said that he needed to be taught appropriate social skills and so implied that she was failing as a parent. Yet, she had two other children at the same school who were progressing well both academically and socially and she was trying very hard to teach him how to share and to recognise the feelings of others, but to no avail.

One professional she saw suggested that Sam was emotionally disturbed as a result of a short separation from her when she was hospitalised when Sam was 3 years old. Initially, his mother wanted to accept this explanation, but as she reflected on this, she felt that this did not adequately explain the nature or extent of his problems. They were very unusual and pervasive.

At secondary school, reports from teachers continued to be negative which affected his self esteem and his parents' being. He was described as inattentive, lazy, defiant and insolent, as the responses he gave to staff when asked, 'What have I just been talking about?' were often exact imitations of what they had said, including intonation and hesitation. He would often look out of the window when they were talking, but he was attending to the topic and could recall the content of what they said.

When his mother finally received the diagnosis, after referral by her GP to a psychiatrist, she was very relieved as the blame was lifted from both her son and herself and she could start to make sense of his problems and devise solutions. It did not solve all the problems at school though, as some staff (who had no knowledge of autism or Asperger syndrome) continued to question the diagnosis - as he looked so 'normal' and he was academically able in many areas. His parents also had to adjust to the fact that this was a lifelong diagnosis and he would continue to need their support and advocacy in adulthood.

Looking back, his parents really wished that one of the many professionals they had met to discuss their concerns had listened more carefully to what they had said. His parents could tell 'Sam was very different' from other children – but they seemed unable to convince others of this.

Helen

Helen is thirty-four years old. She was diagnosed with an autism spectrum disorder and mild learning disability at the age of seven. She has good verbal skills and is literate, although her receptive communication is much lower than her expressive communication. People don't always pick up on this. She likes to be around people but lacks the social skills to develop friendships. Her direct conversational style tends to alienate her peers. She lives in her own flat with weekly welfare visits from a warden. She is fiercely independent and worries obsessively that she will lose her flat if she doesn't seem to be coping.

Because of this, she tends to respond to questions from professionals with set answers that she has learnt will satisfy. She often responds to questions either with 'mustn't grumble' or 'nothing for me to worry about'. People who don't know Helen often don't notice that these are learnt responses. An interview which uses open questions like 'how are you feeling?' will elicit these kinds of responses.

Helen copes with day-to-day tasks by rigidly following routines that have been established over years. However, an unexpected disruption to her routines will cause anxiety, and this can lead her to forget critical aspects of her self-care.

For instance, Helen takes daily medication to help control her anxieties. Without this, her stress levels can get so high that she is unable to function at all. She has a medication dispenser and knows the importance of taking her medication regularly.

Recently, the police were called to Helen's flat because she had smashed a number of its windows. Her warden was called to assess the situation and found her in a highly anxious state. After eliciting the usual rote responses from his general questions, he asked her what time she had gone to sleep the previous night. She replied that she had not slept at all. Further direct questioning uncovered the fact that the new neighbour in the downstairs flat had been playing loud music every night for a week, and in this time Helen had been kept awake all night. Since Helen's priority each day was to follow her usual routines, she had been functioning for a week on almost no sleep.

Despite the fact that this caused such disruption to Helen's well-being, she had not recognised that, by telling someone else, she could get help to solve the problem. Even more worryingly, her warden subsequently discovered that, since the disruption, Helen had forgotten to take her medication, causing her anxiety levels to spiral out of control. This was despite the fact that she knew how important it was and despite the fact that she had followed other routines as normal. Monitoring and direct questioning in this instance were vital to uncover the meaning of Helen's behaviour and help her to address these difficulties.

David

David is twenty-five years old and lives in supported accommodation. He has an autism spectrum disorder. He has expressive communication other than a few signs that are used idiosyncratically, so that only people who know him can understand them. However he understands verbal communication and sign at a concrete level, and has good self-care skills.

David is extremely tactile defensive. If he is touched, even accidentally, by another person, he becomes very anxious and needs to perform repetitive rituals, sometimes for a couple of hours. Interruption of these can result in a full-blown panic attack from David, during which he may lose control to the extent of becoming aggressive.

Fortunately this level of anxiety can be prevented if people around David understand his needs. He needs to be given a lot of time to absorb new information and to prepare for change. If he is given information using speech and /or sign, he may take up to five full minutes to digest it, but when he has done so he will indicate his understanding by nodding. This indicates that he is ready for the next piece of information or the activity.

This kind of communication can seem stilted and requires patience – if David's thought process is interrupted by further information being given too soon, then he may become 'stuck' at that point and unable to move on. However, if he is approached in this way and allowed to take the time he needs, he is able to co-operate with medical examinations, etc. and control his anxieties

George

George is forty years old and has Asperger syndrome. He has no learning disability and is very articulate. His expressive and receptive communication is excellent on a literal and factual level, although he finds it difficult to comprehend subtle social cues or underlying meaning. He lives alone with support from a specialist support worker when he needs it.

The support worker was introduced when it became apparent that George has an idiosyncratic pain response that poses a risk to his health. George does not seem able to link discomfort or pain to a specific health problem, and sometimes does not appear to identify pain at all.

Example: George wears contact lenses, without which he is partially sighted. However he developed a serious eye infection in his left eye, which spread to the right. Although George's physical symptoms were indicative of considerable discomfort (very bloodshot and weeping discharge) he neither complained nor stopped wearing his contact lenses, as most people would be forced to do. When asked if he was in discomfort, George said that his eyes were itchy and sore, but it seemed that he simply accepted this as the situation, rather than concluded that he could or should take any action.

Conversely, from his observation of others, George has developed some knowledge that people react to certain illnesses in specific ways, and he seems to have copied these reactions in his own idiosyncratic manner. For instance, if George has a common cold, he will automatically take three days off work and talk at length about his symptoms.

George's reaction to illness is therefore inconsistent and disproportionate. Despite his abilities in other aspects of self-care, his basic health needs to be carefully monitored.

Peter

Peter is a forty-five year old man. He is diagnosed as having autism and learning disabilities, although he is articulate, literate and appears to have an average I.Q. He lives alone without support. For many years Peter was employed as a hospital porter. This was a full-time post and was Peter's main contact with people.

However, three years ago he was made redundant and this dramatic change in circumstance affected him greatly. With the end of his employment, Peter not only lost contact with colleagues, but also many of his regular routines. His job was also his motivation to care for his appearance and leave his flat, so with this motivation gone, Peter began to neglect himself and spend whole days alone. He became increasingly depressed and de-skilled.

His mother and G.P. arranged an appointment for him to see a psychiatrist, to address his low mood. This took place on a Monday morning. Peter had no expectations of the appointment and although he was co-operative, he answered questions in his typical, literal way, giving exactly the information asked of him and no more.

For example, when asked by the psychiatrist if he was eating and sleeping ok, Peter replied that he was. His mother intervened at this point to ask exactly what food and sleep Peter had taken in the preceding weekend. In a matter-of-fact voice, Peter explained that he had stayed in bed all weekend, and had eaten two crumpets on the Friday and nothing since.

He did not perceive this as a problem, since this is what he had felt like doing, and so it had been his choice. He was not able to make a connection between this behaviour and his general mood, nor place it in context and identify that it was an unusual behaviour for him, or an undesirable behaviour for his general health. Without the intervention and help of a person who knew Peter well, the psychiatrist may not have been able to get this important information from Peter, and so may not have been able to help his recovery (which was a combination of treatment for depression and practical support to re-introduce constructive routines and community links).

William

William is thirty and has just been diagnosed as having Asperger syndrome. He is articulate, literate and lives independently.

William's diagnosis came about as a result of him reading a book on autism and recognising his own difficulties in the descriptions given. William sought advice from the local autistic charity and made an appointment with his G.P. to seek a psychiatric referral. However, six months later, a follow-up call from the charity revealed that William had failed to get a referral and was now in a very anxious state. A long face-to-face discussion with William revealed that, although he was able to make and attend the appointment with his G.P., the anxiety he felt in the meeting prevented him from communicating why he was there. The panic he felt in this situation overtook his usually good communication skills. To cope with the anxiety, his strategy was to sit passively and agree to everything suggested by the G.P.

William suffers from an arthritic condition, for which he receives regular medical attention. In six months he had made three appointments to discuss his suspected Asperger syndrome, but each time, his G.P. had treated his physical condition, unaware that this was not the reason for the appointment.

Despite his abilities, William felt incapable of raising this subject with his G.P., such was the anxiety it caused him, and so it was agreed that an advocate would attend the next appointment with him and speak on his behalf. William's G.P. found this perplexing, since she had known him some years and seen him regularly in that time, but was glad to help him with the referral, which did result in a formal diagnosis for William.

Howard

Howard is twenty years old. He is diagnosed with autism and mild learning disability. He requires 24 hour supervision although he is able to travel by himself and generally chooses to spend his whole day travelling on buses.

Howard lived in the family home until he was nineteen, although he was excluded from school at the age of fifteen. Since that time, college and work placements have failed, so that Howard is used to doing pretty much what he wants.

He would like to have friends but lacks the skills; he refuses to have anything to do with other disabled adults as he perceives them as 'handicapped', unlike him. He has an idealistic concept of friendship: 'A friend is someone you'll do anything for.'

Howard became known to local youths through his travel on buses, and one gang recruited him as 'lookout' while they broke into cars to go joyriding. Howard had no qualms about taking on this role as he saw it as an act of commitment to his new friends (his first friends since childhood). He was an excellent lookout, 100% dedicated to the task. However his career was short as he lacked both the knack of being inconspicuous and the guile to flee when approached, so whilst the rest of the gang always escaped, Howard was caught immediately.

The police have been very sympathetic to Howard's situation and he has so far escaped a criminal record. However, there is a serious worry that Howard places such value on having a friend that he will put himself at risk and agree to any demands in the name of 'friendship.'

Susan

Susan is twenty-two years old and attends an appointment, accompanied by her mother, to request a sick note for work. Susan presents as a shy girl, avoiding eye contact with the G.P. and speaking as little as possible. Initially the G.P. is struck by how similarly the mother and daughter are dressed and wonders if this is a case of an over-dominant parent. Her mother explains that Susan has been off work for two weeks due to stress.

Susan's G.P. asks her about her symptoms. Susan replies that she doesn't know, she doesn't have any. She presents as an immature adolescent and not a twenty-two year old woman. Susan's mother explains that she is not eating and sleeps for most of the day. Her mother says: "Susan doesn't seem to realise that these are signs of stress, she won't admit she has a problem. But her boss says he won't let her come back to work until she gets help. It's taken this long to persuade her to come and see you."

Further discussion with Susan's mother reveals that Susan's employers requested she take time off as she was behaving very oddly at work. She began work as an administrative assistant 4 months ago. Prior to this she had graduated from a local University with a first-class degree in music. The job should have been well within her capabilities but she was soon in trouble for making basic mistakes and working too slowly. In particular she seemed unable to manage her time, which seems strange for a successful graduate.

"Susan couldn't seem to understand what her mistakes were and she just thought that her supervisor was bullying her." Susan's mother explained that she has always used the bathroom as a safe haven in times of stress, which didn't seem unusual in a teenage girl. However at work, she took to retreating to the toilet whenever she was told she had made a mistake, and this developed into her spending most of the day in the toilet.

At this point, the G.P. asked about other aspects of Susan's life. Did she go out, what were her interests? Susan's mother explained that Susan had always been something of a loner, happy in her own company. She had always had a very intellectual interest in music, was fascinated by the work of Handel but completely uninterested in popular music. She was a natural performer but hated one-to-one conversations. She had long-standing friendships with two former teachers, now retired, but no friends of her own age.

The G.P. suspects that this may be a case of Asperger syndrome and broaches this with the pair, who have not heard of the condition. He offers some reading material and websites on this and suggests that he refer them to a psychiatrist with knowledge of ASD, who can investigate this whilst also addressing Susan's stress levels. He does provide a sick note but emphasises that this is short-term solution and recommends that Susan seek additional employment support through the local job centre.

Ellie

Ellie is a 3 year old child who has come into the setting with a suspected ear infection. Ellie's mum says that her daughter has been rocking rhythmically and clutching her ear at the same time. There has been some moisture on her pillow in the morning and Ellie is reluctant to let her mum investigate what is wrong. Ellie is attempting to rock while she is seated on her mother's knee and uses the same repetitive vocalisation "Don't wanna go to the shops" over and over again. She feels hot to touch and will not let the PCP approach her with any equipment. Her vocalisation becomes louder and more insistent when you attempt examination.

STRATEGIES TO TRY

- Ask Mum if her temperature has been taken, if Yes, what was it?
- If No, ask Mum to reassure Ellie that a temperature strip will not hurt her
- Show Ellie the equipment you need to use
- Demonstrate on Mum what you are going to do
- Encourage Ellie to use equipment on you/Mum
- Allow time for Ellie to acclimatise to equipment
- Show that equipment will be used in turns first Mummy, then PCP, then Ellie
- If resistance persists, make second appointment for later in the day
- Use non-threatening environment – Nurse's office instead?

Harry

Harry is a 10 year old boy with Asperger syndrome who has come to the surgery with a suspected sprained ankle. His Mum accompanies him. Although his ankle looks bruised and swollen, Harry is immersed in playing on his GameBoy. You question Harry but the only information you can get out of him is about the injustice of the Sports teacher not allowing Harry to carry playing in the Team game. His Mum says he has valiantly attempted to walk from the car to the setting without any fuss or support.

Harry appears to show no expression of pain and presents as not feeling the obvious discomfort. This could be because his pain threshold is somewhat higher, or he does not know how to express his pain, nor understand the feeling of pain.

STRATEGIES TO TRY

- Ask Harry if he can assist you in your enquiries / to find out more information
- Ask Harry if he will switch off his GameBoy to help you
- Point out the difference between this 2 ankles
- If necessary use a measure to show him the difference
- Ask him what he thinks is wrong and if he feels any pain
- Tell him your diagnosis
- Be absolutely clear, with back up visual information, on what needs to happen next
- Take any questions from Harry to maximise on his compliance
- If initial steps do not work, allow Harry to continue with his GameBoy and tell him that you will need to treat him
- Follow up with visual information and say that will need you to act to help make him better
- Ask Harry if he understands what pain is, has he experienced pain in the past?
- Be advised by the parent/carer who will know Harry and how pain manifests for him

Sarah

Sarah is a 16 year old girl with ASD and moderate learning difficulties who has come into see you for ongoing treatment. A Keyworker from her Care establishment has accompanied her on previous visits but the Keyworker is often a varies. Sarah has come with someone who knows her very well this time but Sarah is responding as if it is her first visit. She asks your name and your date of birth, she appears anxious and is unwilling to sit down or answer your questions. Each time you begin to ask her how she is feeling, she talks over you and does not let you finish. She appears to have a fascination for dates and birthdays and lists of dates are what she keeps repeating.

STRATEGIES TO TRY

- Ask Sarah if she will take turns in speaking with you
- Enlist the help of her Keyworker
- Have a concrete object that symbolises who is talking (e.g a pen or paperweight)
- Hold the object and say "It's my turn to ask you and question"
- Enlist help of her Keyworker in eliciting a reply
- Give object to Sarah and say, "It's your turn to ask me a question"
- Answer Sarah's question in as succinct a way as you can
- Ask to hold the object to signify that it's your turn to talk.
- Continue in this way until you have asked the necessary questions
- * You may also have to involve the Key worker having their turn too

Arjinder

Arjinder is 27 months old and comes to the setting with his Grandmother. Arjinder's family are concerned because he does not turn towards the members of his family when they come into the room and despite them calling his name, he does not seem to show any recognition of his name nor the significant people in his life. Arjinder has had a hearing test and all appears to be normal.

While Arjinder is sitting on his Grandmother's lap during the consultation he seems to be hearing the whir of the computer fan on your desk and occasionally turns towards the ticking of the clock on the wall. Arjinder does not respond to his Grandmother's voice and does not show any particular reaction when you mention him by name.

You wind up a toy in front of him and he immediately pays attention to the winding noise and the

subsequent actions of the toy.

STRATEGIES TO TRY

- Ask Grandmother what his preferred activities are at home
- Try more subtle sounds near to his ears – (e.g. jingle bells, the crunch of the stapler, a tapping pencil)
- Ask Grandmother to whisper his name and then gradually increase the volume to gauge his response
- Try repeating a nursery rhyme over and over at different volumes to see which level of tone and pitch he appears to attend to
- Ask Grandmother what would reward him for a response – it may not be a traditionalism
- Work on trying to find a suitable reward for paying attention to adult voices and ask for this to be consistently applied at home by all family members

Sun Li

Sun Li is a 5 year old child who has come to the setting because he has not developed any anticipation of needing the toilet and cannot yet assist with dressing and other self-care skills. He is incontinent and very dependent on the help of his family to look after himself. His reception class have also pointed out his dependency and are wondering if he needs additional classroom support.

Sun Li's mum says her son gets very engrossed in his collection of toy cars and although she reminds him about going to the toilet, he waits until it is too late and will wet and soil himself. His toy car collection must be at his side wherever he is and he will play with their wheels and opening car doors while his Mum attends to his care needs. Sun Li has brought 2 cars with him to the setting, mum says he will reduce the number in his collection from 32 to 2 according to where they are going. He takes 2 into school with him.

STRATEGIES TO TRY

- Show an interest in Sun Li's 2 cars
- Ask him to give one to you to hold while you talk
- If yes, ask him to hold the other car and you will give him the other one back when you have finished
- If no, ask him to hold 2 cars but rest them on the table quietly
- Talk to Mum about using the cars as an incentive for tasks and a reward for completion of tasks
- Advise using the cars to insist on "a time and a place"
- Develop a way to visually convey to Sun Li what is needed in self-care routines (e.g digital images of him dressing, sitting on the toilet)
- Work out a finely graded programme that relies on visual images showing every step of a process - (put hands in vest, lift arms, put vest over head, pull vest over shoulders, find armholes, put one arm in etc)
- This approach can be used for most self-care skills including toileting
- The idea will be to involve Sun Li taking an active part in each activity, while his cars remain "parked" – a visual symbol or marked spaces on a piece of paper.
- Mum/family stipulate the number of cars that can be present – start off with 10 and gradually reduce.
- All cars may be played with after complying with the requirements of each activity
- Use timer to provide visual/audio cue for when playing with cars is over

Jenny

Jenny is a 15 year old who has ASD and severe learning difficulties. She has come into the setting with her mother as she has severe friction sores around her genitals. Her mother says that Jenny has masturbated since she was 13. Jenny is now attempting to masturbate whenever she is not occupied at home or at school. Jenny will attempt to use her hands to masturbate, but will also rub herself against corners of furniture, arms of chairs, door handles and other household objects.

Although Jenny engages in masturbation often she does not seem to have any climax to her activity, as a result she has started to masturbate with increased frequency at times that her parents cannot supervise (on school transport, at the respite care service and when parents have a local babysitter). This has become a very embarrassing topic for them and is threatening to reduce their arrangements for time on their own.

STRATEGIES TO TRY

- Infection and sore areas need examination and treatment
- Be guided by her mother on how to do this
- Aim to keep Jenny calm during examination by diverting her hands and her attention
- Discuss with her mother what Jenny's preferred interests are
- Plan how to intervene in attempts to masturbate by using diversion to preferred interests
- Suggest introduction of a visual means of showing that masturbation is a "private time" activity (i.e. in her bedroom).
- Visual prompts can also be used to ensure direct movement from area to area (thereby eliminating door handles etc)
- Visual means of conveying expectations can be used as a universal system for school, transport, respite care and babysitter
- If there something in Jenny's interests that will help to divert her hands ?
- Are there gross motor pursuits (eg climbing, bouncing, cycling that will divert Jenny's physical energies?).
- Restrictive clothing (eg dungarees) should only be used when all else fails
- The aim is to give alternative activities with less frustrating outcomes, not to punish or remove attempts to masturbate
- Masturbation can be seen in a "time and place" context
- Explore community agencies to assist in teaching masturbation to a successful outcome

Hannah

Hannah is 3 years old and attends the setting with her foster carer. Hannah can communicate but the main substance of her use of language is the recitation of "The Little Mermaid" Disney film. Answers to questions tend to be short and to the point, often monosyllabic before she will return to talking like Ariel, using whole passages of monologue. Her foster carer says Hannah is obsessed by the video and insists on watching it all the way through after breakfast and before bed time. Any attempt to cut down or miss out showing the video results in severe tantrums and lashing out at her carers. Hannah has come to the setting with a suspected bead lodged in her ear.

STRATEGIES TO TRY

- Discuss with her carer the circumstances and the best approach for Hannah
- Show Hannah the equipment to be used
- Demonstrate on yourself and the carer what you will need to do
- Use a doll and the name Arieto demonstrate your examination of her ear

- Ask Hannah if she is ready
- Allow time for her answer
- If yes – proceed
- If no re-demonstrate and ask her carer to assist
- Give time for Hannah to process instructions and avoid use of force
- The use of her obsession may be the key to ensuring her compliance

Marvin

Marvin is a 16 year old teenager with Asperger syndrome. He attends the setting complaining of swollen glands and a throbbing headache. His father accompanies him. Marvin is keen to establish what is going to happen in the consultation and asks questions like “Will it hurt?”; “Do you want me to take off my jumper?”; “Have I got to lie on the couch?” He tries to divert your attention by asking you where you do your weekly shopping and volunteering the information that his family go to Sainsbury’s every Friday night. Marvin appears to be stressed by the circumstances, but you also need to do a thorough examination.

STRATEGIES TO TRY

- Ask Marvin to relax and breathe deeply
- Ask Marvin questions about his symptoms in simple language
- Give Marvin the opportunity to reply fully, but if he cannot, ask his father
- Ask Marvin to point to the areas that are causing pain
- Tell him what you are going to do in examination
- Show him the equipment and encourage him to ask questions
- Check that he has understood what is required
- Continue to talk to him about what you are doing
- Give him praise for his co-operation

If he cannot relax, use a diversion of his attention and involve his father in assisting your examination.

Honey

Honey, a 30-month old child with ASD and developmental delay attends an appointment with her Nanny (childminder). She has been rubbing her eyes a lot and has developed an infection in both eyes as a result. Honey’s parents and Nanny do not know why Honey has been rubbing her eyes so much, but it is typically occurring when they go into brightly lit places – like the local supermarket and the shopping mall. Around the house or in natural daylight, there do not seem to be any problems.

STRATEGIES TO TRY

- An eye examination needs to be undertaken
- Use your judgement on how to approach Honey, following guidance given in Topic 2 Section 1 – ACER – ask, check, explain and reinforce/repeat
- Enlist the assistance of the Nanny to ensure Honey’s cooperation
- Discuss details of when Honey is rubbing her eyes and where she is looking as she does it
- Explore whether this is a self-stimulatory activity that gets adult feedback
- Discuss possibility of visual sensory overload
- Advise monitoring visits to overlit venues to check on this being a possible cause
- If possible sensory overload, discuss the need for Honey’s to visit such venues and/or mediation of the effects e.g. wearing baseball cap; sunshade or sunglasses or providing laptop

occupation for Honey that might mediate the effects

Joshua

Joshua is a 13 year old boy with ASD and limited receptive and expressive language skills. Joshua attends his appointment with a care worker from his residential special school. Joshua can use a communication system called the Picture Exchange Communication System which relies on using pictures and words on cards to convey meaning. Joshua's Care worker has used this to good effect to help Joshua understand why he has attended this appointment. He sits quietly while his care worker explains why he has come to see you.

Joshua has a very limited diet and his parents and the care staff are worried that he may not be getting the full range of nutritional value from his food. As he is starting puberty his weight is beginning to be a concern, compared to the norms for his height. Joshua has always preferred strong tasting, spicy foods and will refuse some meals because they do not match his preferences.

STRATEGIES TO TRY

- Take weigh and measure height for the record
- Question carer on typical food intake in the day
- Discuss ways in which Joshua's food could be made more spicy/tasty by the addition of herbs and spices
- Encourage the carer and staff to use Joshua's PECS system to give him food choices, rather than opting for a straight refusal
- Ask school to keep a food diary
- Look at choices for alternative sources for nutrition from other foods
- Be aware that a preference for strong tasting food can be common for people with ASDs as blander food does not stimulate their gustatory sense.

Jake

Jake is 7 years old and has high functioning autism. He attends the setting with his father. Jake has been experiencing severe facial pain and sensitivity in his teeth and gums. His father begins to describe the symptoms that Jake has articulated, but he is interrupted frequently by Jake who insists on correcting minor errors and use of language in a pedantic way. This makes the task of assembling the facts difficult for the practitioner and it appears that Jake is using pedantry to delay the need for your examination. His father is becoming more stressed by Jake's verbal interruptions and Jake is apparently stressed by the appointment.

STRATEGIES TO TRY

- Ask both his father and Jake to help you gain a picture of the symptoms
- Deal with their responses on a turn taking basis
- Ask Jake to add more information to what his Father says OR
- Ask Jake solely to describe his symptoms
- Check with Jake that you have got a full description
- Tell Jake that you will have to examine the source of his pain and will try to avoid hurting him
- Ask him if he would like to be given some time to calm down first
- If Jake has his own system of stress relief, suggest this is used OR
- Suggest stress relief via deep breathing; manual occupation or manipulation of a stress ball, for example.
- Give Jake time to be more relaxed and then fully explain what your examination will entail

- Ask Jake for any questions before you proceed
- If Jake continues to try to control the conversations, then revert to the turn-taking idea to give yourself a full opportunity to explain.
- In consideration of his young age, then show him the equipment to be used and provide a demonstration if necessary

Finn

Finn is 12 years old with ASD and Moderate Learning Difficulty. He attends the setting as an emergency case with his form teacher from school. Finn has asthma and has come to see you because of a potential allergic skin reaction to using mohair and alpaca wool in his lesson on textiles. He is breathing in a shallow way and he is clearly stressed and upset about having to come to the setting as an emergency. Finn has a piece of string that he is holding up in front of his eyes. It rotates one way, then the other and then Finn holds either end and pulls it tight. His form teacher says this is an habitual routine that Finn employs during times of stress.

STRATEGIES TO TRY

- Try to use the string routine to help to calm Finn down
- Ask him to breathe in time to the particular movements of the string
- Ask his form teacher to assist you in this and model a steady rate of breath
- Ask the form teacher to give you background to the skin reaction, while you are encouraging steady breathing
- Find out details of the management of Finn's asthma
- Assess level of intervention needed, once you feel Finn's stress levels are declining
- You may also wish to use other de-stressing activities but often it is better to start with a strategy that the patient has devised
- for themselves rather than introducing anything new.

Samad

Samad is a twenty year old man with autism and learning difficulties. New and unknown situations and people make him very anxious. He has recently moved from the family home, which is outside your area, and into a local group home. Your surgery treats the residents of this home, who have a range of disabilities. The Home Manager has informed you that Samad was used to being the centre of the family's attention, and was always given medical treatment within the family home.

Because of this you have undertaken home visits with Samad in the first months, following a pattern suggested by the Home Manager. These visits have gone well. However, they are keen for him to learn new skills and want him to attend appointments in the surgery. This would make your life easier in some respects, but your surgery is a large and busy one, and it is important that this appointment does not cause disruption for your colleagues and other patients. You and the Home Manager agree a plan as follows:

- An examination room is booked to be free for ½ hour either side of the appointment. It is agreed that Samad can go straight to this room, rather than the waiting room. This is a room that can regularly be made available.
- The Home Manager visits and makes suggestions about aspects of the room that can easily be adapted to help Samad cope with the situation. (She suggests using the desk lamp rather than overhead strip light, tidy materials from surfaces, and removing unnecessary chairs to create more space).
- The Home Manager arranges to meet with the entire staff group and run a ½ hour staff

development session on ASD. She brings a photograph of Samad so that they will recognise him when he visits.

- On the day of the appointment, the Home Manager calls reception before setting off, so that Samad and his supporter are expected by reception when they arrive and can go straight to the examination room to wait. Your plan is designed to make the surgery immediately accessible to Samad, with the aim of reviewing the plan to reduce the need for this level of support in time.

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Useful Resources, contacts and websites

Sign Guideline Number 98 - Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders

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In development:

SIGN Guideline on Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorder. A National Clinical Guideline. Publication date winter 2006.

Scottish Intercollegiate Guidelines Network (SIGN) www.sign.ac.uk

NHS Education for Scotland has produced the booklet *Information for parents and carers with a child or young person recently diagnosed with an autism spectrum disorder*.

The booklet can be requested from the Scottish Autism Service Network by calling 0141 950 3072 or downloaded from www.scottishautismnetwork.org.uk

The Scottish Society for Autism, Hilton House, Alloa Business Park, Whins Road, Alloa, FK10 3SA. Tel: 01259 720044.

www.autism-in-scotland.org.uk

The National Autistic Society-Scotland, Central Chambers, 109 Hope Street, Glasgow, G2 6LL. Tel: 0141 221 8090

www.autism.org.uk

Scottish Autism Service Network, Room D002, David Stow Building, The University of Strathclyde, 76 Southbrae Drive, Glasgow, G13 1PP. www.scottishautismnetwork.org.uk

National Centre for Autism Studies, University of Strathclyde, Sir Henry Wood Building, 76 Southbrae Drive Glasgow,

G13 1PP. www.strath.ac.uk/autism-ncas

Centre for Education and Training (CETA), New Struan School, A Centre for Autism, Bradbury Campus, 100 Smithfield Loan, Alloa, FK10 1NP. Tel: 0845 300 9282.

www.autism-in-scotland.org.uk/training

Enquire. **The Scottish Advice Service for Additional Support for Learning**.

Helpline:0845 123 2303. www.enquire.org.uk

The **Mental Health Foundation** produces the information booklet All About Autistic Spectrum Disorders. Publications, The Mental Health Foundation, 9th Floor, Sea Containers House, 20 Upper Ground, London SE1 9QB. Tel: + 44 (0) 20 7803 1100. Fax: + 44 (0) 20 7803 1111

Website: <http://www.mentalhealth.org.uk>

Medical Research Council

website: : <http://www.mrc.ac.uk/>

The National Autistic Society (Office: 020 7833 2299; Helpline: 020 7903 3555)

Email: nas@nas.org.uk;

website: <http://www.nas.org.uk>

Terms used in the Resource

Autism Spectrum Disorder (ASD)

Autism spectrum disorder is used to cover a number of subgroups, which have the triad of impairments in common. This is usually taken to include Asperger syndrome, autism and pervasive developmental disorder, not otherwise specified (PDDNOS under DSM IV; atypical autism being the term used in ICD-10). However, there are more informal labels that are also usually considered to be part of the autism spectrum. These include Kanner's syndrome, classical autism, High Functioning Autism and semantic pragmatic disorder. Debate continues on the validity of the distinction between all these subgroups. The resource is relevant for ALL individuals considered to have an ASD, regardless of any particular label within it.

Health care setting

This term is used to refer to any setting within which primary health practitioners might work (eg clinics; surgeries; centres; outpatient settings).

Parent/carer

These terms are used to cover parents and all others (professionals, friends or voluntary sector staff) who might be supporting or advocating on behalf of a child or adult with an ASD.

Patient

Throughout the resource, the word patient is used to refer to a person with an ASD only in situations where it would also normally be used with reference to the general population. People with an ASD are not deemed to be patients simply by virtue of their diagnosis (ie ASD is not an illness). This term is used to denote any professional who is working in the health care system at the primary care level (eg General Practitioner; Allied Health Professionals (eg dietitians, occupational therapists, physiotherapists, podiatrists and speech and language therapists), Dentists, Opticians, Public Health Nurse; District Nurses; Practice Nurses; School Nurses; and Dental nurses).

General population

This term is used to refer to those who do not have an ASD or other known disorder and who are considered to be following, or have followed, the usual developmental route.

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<http://www.nes.scot.nhs.uk/asd/glossary/index.htm>

Contact Us

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Web Directory

[Directory of individuals and teams undertaking assessment and diagnosis of autism spectrum disorder in Scotland \(pdf\)](#)

Project Teams

The content of the resource was commissioned by NHS Education for Scotland (NES) and produced by the Autism Team at the University of Birmingham.

[University of Birmingham Autism Team](#)

[NHS Education for Scotland \(NES\) Autism Spectrum Disorder Steering Group](#)

University of Birmingham Autism Team

Professor Rita Jordan has served on national and international task forces and working parties set up by governments or professional bodies to review evidence and offer advice in relation to ASDs (eg the Irish Task Force, British Psychological Society, Department for Education and Skills, and was a core member of the working group which developed the National Initiative for Autism: Screening and Assessment Report in 2003.

Karen Guldberg has taught children with autism in a variety of settings and is currently Programme Co-ordinator for the web-based University Certificate and Certificate of Higher Education in ASDs. She has been responsible for the development of the programme content and learning environment from its inception and has, through this, developed extensive expertise in the adaptation and dissemination of knowledge through the web and other alternative learning environments such as CD ROM.

Dr Glenys Jones has been engaged in research for the last 20 years on different aspects of provision for children and adults with autism and ASD. These include research projects commissioned by the Department for Education (Jordan, Jones and Murray, 1998), the Department of Health in England (Jones, Meldrum and Newson, 1995); and the Scottish Office Education and Industry Department (Jordan and Jones, 1996). She is Editor of the Good Autism Practice Journal published by BILD.

Andrea MacLeod has worked for a large charity in ASD. She has an MEd in Autism: Adults and has supported adults with ASD and learning disabilities in residential provision and set up and run a service for supporting adults with Asperger's syndrome in the community.

Lynn Plimley has worked in the field of autism for 25 years and was Principal of a specialist school for autism. Currently, she works on the Webautism programme at the University and for a national charity in Wales – Autism Cymru. She is the book reviews editor and an Editorial Board member for the Good Autism Practice Journal.

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