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Autistic Spectrum Disorders

Information for Dentists and Opticians in Wales

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This document is written primarily for dentists and opticians but the content and strategies contained within will also be of interest to other Healthcare providers located on High Streets and in Community and Hospital settings.

What are Autism Spectrum Disorders?

Autistic Spectrum Disorder (ASD) is a life-long complex neuro-developmental disorder restricting a person's ability to communicate and relate to others impacting upon how individuals make sense of the world around them. For many their everyday environment can be a bewildering and sometimes frightening place.

ASD affects around one in every 100 people and the more accessible and publicly recognisable term 'Autism' is often generally used as a short hand for ASD. Males are four times more likely to have autism and the impact upon individuals families can sometimes be devastating. ASD may occur in association with any level of general intellectual/learning ability and manifestations range from subtle problems of understanding and impaired social function through to severe and profound disabilities. Some people with autism are able to live independent lives whilst others may need a lifetime of specialist support.

Currently there are no effective means to prevent ASD, no single effective treatment and no known cure. The large body of literature on ASD around today suggests that the earlier the intervention takes place, the better the outcome. Early referral for assessment and diagnosis will therefore enable the person with ASD to access the most suitable advice and support although it is recognised that Autistic Spectrum Disorders are under-diagnosed in the adult population. The term ASD also encompasses many sub-groups such as:

- Asperger syndrome.
- High functioning Autism.
- Classical Autism (sometimes known as Kanner's syndrome).
- Pervasive developmental disorder (PDD-NOS).

People in these sub-groups may experience difficulties in three main areas: impaired social interaction; problems with verbal and non-verbal communication; and very specific rigid routines and repetitive behaviours.

To summarise, some of the impairments can appear, at first glance, to be quite mild especially in Asperger syndrome but the underlying condition can have a profound impact upon an individual's ability to cope with the rigours of daily life. The effects on people with Autism vary and not every characteristic is evident in every person.

General Implications for Practice

This section identifies several of the key features of ASD which you should bear in mind when you see individuals with ASD in your practice. Top of the list are the implications arising from the difficulties and especially hypersensitivities that individuals with autism have in responding to sensory stimuli.

The effect of over-stimulation in one or more sensory area may result in patterns of behaviour including complete withdrawal to repetitive patterns of behaviour such as flapping or rocking through to more challenging behaviours. So what are some general points to bear in mind in relation to Dentistry and Ophthalmology?

Visual Stimuli:

Sensitivity to light, especially fluorescent lights and for example pen lights will need to be borne in mind within the surgery. Certain colours or a busy visual display may also be unsettling.

Smell and Taste:

Some people with ASD may dislike the taste and/or smell of mouthwash or toothpaste used at the dentist. Indeed a dislike to some smells may cause refusal to enter some environments.

Touch:

Some people with ASD dislike being touched by others. As part of the health examination simply the very close proximity of the optician or dental surgeon, the sensation of a cold instrument entering the mouth or the ophthalmoscope peering into the eye may well be unsettling for the person with ASD.

Hearing:

Noise can also present a problem; so please consider the noise of electronic machines to the rattling of instruments. Temperatures of equipment may cause distress as well.

It is therefore well worth being prepared by finding out about the individual's sensitivities to light, smell, taste, touch, and noise before you examine them.

Social Communication:

Many people with ASD often have problems with understanding aspects of the new situations and have difficulty engaging in conversation and processing information. They may also have particular difficulty in understanding facial expressions and tone of voice, common phrases and sayings but also have difficulty in understanding humour so sarcasm and jokes are likely to achieve little response. Please therefore give individual's with ASD in your practice extra time to process verbal information; instructions or questions and give extra time for their response.

You may well find that those with Asperger syndrome have difficulty in starting and sustaining conversations, but once commenced conversations tend to be one-sided with the person displaying an intense interest in a particular topic.

Impairments in social interaction may mean that individuals find it difficult to interpret when others are not interested in the topic.

Social Imagination:

It is apparent that people with Autism have great difficulty in analysing situations and can have difficulty interpreting and predicting other people's intentions and behaviours.

Individuals can struggle with change, unfamiliar situations and do not understand certain concepts such as danger and role-play.

General Strategies for Care

Accessing Health Care:

People with an ASD, whether diagnosed or not, often experience difficulties in accessing health care services. Many healthcare services require a patient to seek an appointment assertively; to be able to visit a healthcare service; and to explain their difficulties to an unfamiliar person. An individual with ASD will lack the skills needed to be able to do some or all of these, and will therefore need support accessing healthcare services. Many of the difficulties experienced can be eased or eradicated with a little preparation, knowledge and understanding. From reception staff to healthcare practitioners, all healthcare staff play an important role in being able to support the individual to access services.

Appointments

People with ASD may find it difficult to communicate the need for an urgent appointment and find changes to their daily routine stressful. If possible it may be necessary to offer the assessment/examination in the choice of preferred language e.g. Welsh. Some people with ASD take things very literally, so if they have an appointment at 9.00 am they will expect it to be exactly on time. If possible it might be advisable to see a patient with ASD at the start or last appointment of the day when there are not as many people around.

For children with ASD it may be useful to plan an informal visit prior to consultation. Arrange a visit on a quiet day to help to prepare them for their visit.

Introduce the child to everyone at the practice such as the receptionist. Allow the child to sit in the dentist/optician's chair.

A double appointment may be necessary to facilitate the patient's treatment or allow for any possible delay. If there is a delay with the appointment, keep the individual informed of the delay. If possible try to give the patient with ASD the last or first appointment of the day. Keep to appointment times, minimise waiting times and from the beginning spell out that will be a start and finish to the process including, if possible times.

Communication

Be aware of literal interpretation being attached to requests you make. For example, if you were to say "would you like to sit in the chair," the answer may well be "no" So, say what you mean, "Please sit down" is a direct request. Similarly with: "I will be a minute" the individual with ASD will expect you to mean a minute.

Do not be alarmed if minor social interactions are not reciprocated (e.g. shaking hands, using 'goodbye' and similar). People with ASD are not noted for their social banter, so do not be concerned if replies tend to be monosyllabic or pedantic.

If you know a procedure is going to be painful or simply because you are getting very close to the individual then say something like 'this might feel a bit unpleasant just for a moment' or similar. Phrases such as 'this won't hurt much' are too ambiguous.

Language using metaphors or idioms can also be taken literally, so it is good practice not to use common idioms such as 'she has butterflies in her stomach'.

Conversation can be difficult for the person with ASD who may interrupt you or not reply. There can be problems with knowing when to reply resulting from difficulties interpreting many of the communication cues which are commonly used.

A person with ASD can also have processing problems so may still be processing what you have said when you are expecting a reply, so giving time for processing is good practice. You may need to use short sentences with a clear meaning and please do not assume a non-verbal patient doesn't understand.

A person with ASD is likely to have poor skills when using and interpreting facial expression and body language, this can lead to them not recognising signs usually picked up from facial expression e.g. surprise or annoyance. You may also get no eye contact from a person with ASD; (or even less commonly a fixed stare), this does not mean they are not listening.

Examinations / Hypersensitivities

A physical examination can be difficult for anyone, even more so for the individual with ASD. If the individual is very anxious about visiting the service, they may need time to explore and become used to the environment, people and equipment. A number of appointments, visiting and exploring before gradually building up to the examination may help.

Hypersensitivities may mean that even the slightest touch is not well tolerated. Noise can also present a problem; so consider the noise of electronic machines or rattling of instruments. Temperatures of equipment may cause distress as well. It is well worth being prepared by finding out about the individual's sensitivities beforehand.

Individuals with ASD may have difficulty in predicting behaviours of others. Whilst certain behaviours such as putting on examining gloves may indicate that an examination is going to start to people without ASD, those with ASD may not see this as a cue. You may need to verbally prepare for the start of an examination.

Most individuals with ASD prefer predictability to being met with the unknown. Explaining exactly what will happen during the physiological intervention, including what the individual will feel and experience as well as how long the procedure will take can help to reduce anxiety.

Parents and carers are experienced in dealing with the individual; enlisting their help or advice may be of great benefit.

Fears and phobias are more common in individuals with ASD. If the individual has a specific phobia they may need specialist support to help with desensitisation.

Some helpful ways to adapt your practice:

- Be patient, the individual may need a number of visits before being ready to engage.
- Seek information about sensory problems before the appointment.
- Adjust the environment to meet the needs of the individual where possible.
- Discuss the examination / procedure with the individual before starting. Explain what will happen, what the individual will experience and how long it will take.
- Continue to explain what is happening during the physical intervention.
- Use verbal prompts, don't rely on the individual interpreting your behaviour / body language.
- Enlist the help and advice of family / carers where appropriate.
- Seek specialist support for specific phobias.

Dentistry and ASD

In recent years there is an increasing body of evidence suggesting that children with autistic spectrum disorders require special dental management to improve their oral hygiene as well as their dental aesthetics with the implication being that more care from general dentists, and periodontists and orthodontists should be provided routinely to autistic individuals with ASD.

It is therefore generally recognised that individuals with ASD tend to have poorer oral hygiene resulting in tooth decay and gum disease. What are the reasons for this?

Undoubtedly nutritional diet plays an important part in this process where soft sticky foods can be the food of personal preference in ASD and due to their desire for 'sameness' there is very little variation beyond this diet.

Occasionally some individuals display self-injurious behaviours and repetitive actions such as teeth grinding (Bruxism) of teeth will, over a period of time, have considerable effect. Medication occasionally used in ASD such as anti-convulsants where epilepsy is present, SSRI's for anxiety or depression, or even anti-psychotics can all lead to dry mouths and therefore impact adversely upon dental hygiene.

Dentists will often find that parents of children with ASD are very good sources of information and guidance concerning their child's capacity to accept physical examination in the dental chair. So enlist the parent's support and advice early in the process!

Further, parents can be a good aide for dentists whilst performing procedures with individuals with ASD. Dentists will find that Behaviour Guidance Techniques such as positive verbal reinforcement, 'tell-show-do', distraction and rewards are all techniques which have been shown to be helpful with patient with autism and parents can be very good sources of suggestions of what works and what doesn't for their son or daughter.

Thinking the through the eyes of the person with autism is a good start for the dentist, for the world can seem an unpredictable and frightening place for anyone with autism. Therefore having just an insight rather any deeper knowledge into the nature of autism can be extremely useful in enabling the dentist to provide a caring and responsive service from which the individual can benefit. So, an appreciation of the difficulties of social interaction, of the hypersensitivities to light, sound, touch, taste and smell, of

the difficulty in adapting to new environments can give clues as to the approach to be used.

Preparation for the visit is something which can pay dividends. For people with autism concrete experiences of a situation rather than in abstract are likely to increase the chances of successful visits and therefore for treatment.

The Community Dental Service in Wales has developed strategies for introducing the patient with autism to dental care and suggests the use of visual aids such as digital photography to create a story about visiting dentist; an initial home visit for assessment, and a gradual process of acclimatisation (Griffiths and Greening 2004).

Individuals with ASD can be either under or over sensitive to pain so a key feature in the treatment process by dentists will be the administration of a pain relieving injection. If the patient needs an injection or blood test, then it will be a good idea to try and divert their attention elsewhere as suggested earlier. As before, the use of visual clues pictures or a doll can be helpful in demonstrating what is going to happen and the use a local anaesthetic cream such as EMLA cream to numb the site of injection can also be an advantage.

Ophthalmology and ASD

The Optician needs to be aware that some people with autism appear to have problems seeing things clearly and this will contribute to their general perception of the world appearing disjointed, confused and often frightening. For example, other people and objects may seem blurry, move around or even disappear. Text may flicker during reading, words double or shadowy lines appear on the page.

There is a belief in some areas that these perceptual disturbances are caused by a condition referred to as visual stress. It is therefore reasonable to assume that the way in which the brain processes visual and other sensory information is the

key to many such disturbances. One approach to meet the challenge of this sensory overload has been taken by the Irlen Institute in the USA who have developed precision-tinted coloured overlays and filters for lenses. Some people with ASD have reported beneficial outcomes since using these lenses.

However the role of the Optician will be to examine the physical health of an individual's visual sight and to recommend any remedial course of action necessary.

Preparation for the visit will be key to ensuring a good outcome. The use of visual clues perhaps via the use of digital photography, to create a story about a visit to the Optician can be very helpful as preparation for the visit.

Often equipment used by Opticians and the sheer nature of the very necessary close physical examination may be daunting. If it is at all possible to create the opportunity for the person to visit the Opticians in advance of the real examination, to sit in the chair, to see, feel and to try on the heavy glass frames used in the examination.

A possible useful plan is to arrange the appointment at a time when a sibling or other known and 'friendly' person is being tested so the individual with ASD can follow after them and can observe for themselves that no distress has been caused. Indeed the role of the parent/carer will be really important as a source of information and suggestions for strategies which the optician can employ but also as means of soothing, and reassuring the person with autism to ensure a successful outcome.

Referral to Other Services

A visit to another service with different agencies can cause many problems for a person with ASD as they will be moving from the familiar situation with you into an unfamiliar situation.

If the service is prepared they are more likely to be able to adapt to fit the needs of the individual with ASD.

Therefore please ensure that your referral contains the necessary

information about the individual including the strategy you found best to work with him/her.

Making a difference to the health of a person with ASD may go slowly at first, but determination can bring positive results and invaluable rewards. By adopting the strategies discussed in this booklet, you can have a significant impact not only on your patient's health but on their quality of life as well.

Helpful links and sources of further information

Links within Wales:

- Griffiths, J & Greening, S (2004) Autistic Spectrum Disorders and Oral health :
- All Wales Special Interest Group For Oral Health Care. 1st Welsh International Conference in the Developments in Autistic Spectrum Disorders, Cardiff 2004.
www.awares.org
- In April 2008, the Welsh Assembly Government published the world's first Government action plan for autism and this strategy has led to a local ASD lead being identified within every Local Authority area in Wales. You can find out who your local ASD lead is by contacting your local Social Services dept or by contacting the Welsh Local Government Association (tel 02920 468600). The WLGA is the home for three ASD regional support officers who will also be able to give you the information you require. Make sure you receive by email regular copies of the WLGA ASD Strategic Action Plan newsletter, which updates autism progress and practice throughout Wales, simply give your email address to the WLGA ASD Regional Support officers (ASDinfo@wlgaco.uk)
- In 2010 The Welsh Assembly Government announced that it will be working with Local Health Boards in Wales to establish an All-Wales Network for the assessment and diagnosis of adults with ASD.

Also in 2010 The Welsh Assembly Government also commissioned an evaluation into children's ASD assessment and diagnostic services.

- Also in Wales from 2010 the new Wales Autism Research Centre (WARC) was launched and is located in the School of Psychology, Cardiff University. The Director of the autism research team is Professor Sue Leekam, Chair in Autism. The research centre's website is www.cardiff.ac.uk/psych/home2/warc/
- Autism Cymru operates www.awares.org a bi-lingual information site for autism in Wales and this site also hosts the world online autism conference every autumn which includes many of the world's most prominent clinicians, researchers and practitioners in the field of autism.

Links within Wales:

- The National Autistic Society website contains very useful guidance and advice for health practitioners www.nas.org.uk
- Adam Feinstein, who is both a parent of a young man with autism and is employed in Wales by Autism Cymru, is the author of 'A History of Autism, Conversations with the Pioneers' published by Blackwells/Wiley. This includes the most accurate history to date of autism; the way it is currently viewed throughout the world; and the approaches being used by governments and those working with people with autism. This book is viewed as a modern classic in the disabilities field.

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