Autism in adults

Autism spectrum disorder is a complex life-long neurodevelopmental disorder that affects 1.1% of the UK population. It is a social communication disorder that is characterised by rigid and repetitive routines or behaviours. It is also commonly associated with difficulties in cognition, behavioural flexibility, sensory processing, emotional regulation, and altered sensory sensitivity.

The GP curriculum and autism in adults

Clinical module 3.11: Care of people with intellectual disability requires GPs to:

- Recognise that in every consultation you must make the effort to identify, monitor and review the progress of all patients who have difficulties with communication, social relationships and managing their own affairs
- Be aware of the atypical morbidity and mortality prevalent in patients with intellectual disability (and autism) and the atypical presentation of acute and chronic physical and psychiatric disorders
- Be aware of the additional skills of diagnosis and examination needed in patients unable to describe or verbalise symptoms and where to obtain specialist advice and help

Clinical module 2.01: The GP consultation in practice requires GPs to understand that:

- Clear, sensitive and effective communication with your patient and their advocate is essential for a successful consultation
- Negotiating management plans with the patient involves balancing the patient’s values and preferences with the best available evidence and relevant ethical and legal principles

History and classification of autism

First described as a separate entity by Leo Kanner in the USA in 1943 and Hans Asperger in Austria in 1944, autism did not appear in the International Classification of Diseases (ICD 9) until 1977, and then in the Diagnostic and Statistical Manual of Mental Disorders (DSM 3) in 1980. It was described as a triad of impairments with variable intelligence quotient and language development. See Box 1 for the three ‘impairments’. The number of subgroups increased significantly over the following years, and included autism, Asperger’s syndrome, atypical autism and pervasive developmental disorder.

The latest DSM 5 published in 2013 brought all the groups together under the blanket diagnosis of autism spectrum disorder (ASD) (American Psychiatric Association, 2013). It is not yet known if ICD 11 (currently in development and expected in 2018) will follow the same path, but it is likely.

DSM 5 also describes a dyad rather than the previous triad of impairment with the two components being:

- Impairment in reciprocal social interaction, and
- Rigid or repetitive behaviours

The decision to create a single ASD entity arose as the separate diagnoses were not applied consistently across different clinical settings. The decision in DSM 5 to link social interaction and communication together relates to the communication deficits experienced by those on the autistic spectrum, even when apparently being fluent in language skills.

Anyone previously diagnosed with one of the four pervasive developmental disorders in DSM 4 should still meet the criteria for ASD in DSM 5. Additionally, under the DSM 5 criteria a person with ASD must show symptoms from early childhood, even if those symptoms are not recognised until later in life. This change encourages earlier diagnosis of ASD, but also

Box 1. Triad of impairments.

- Social interaction
- Communication and imagination
- Repetitive stereotype pattern of activity

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allows people whose symptoms may not be fully recognised until later in life to receive a diagnosis.

From a general practice perspective, the only change we are likely to notice is that there will be no new patients diagnosed with Asperger’s syndrome, as the term has been dropped. However, there are many people with ASD who identify strongly with a diagnosis of Asperger’s syndrome, and the term is likely to stay in popular usage for some time to come.

**Benefits of diagnosis**

It is important to recognise that there is no ‘treatment’ for the core features of autism. So why diagnose ASD in adults?

Only 15% of adults on the autism spectrum and without intellectual disability are in full time employment. It is estimated that ASD costs the country £32 billion per year (Knapp, Romea, & Beecham, 2009). This makes it the single-most-costly health condition, exceeding cancer, heart disease and stroke. This is mainly due to lost opportunities for employment or independent living, expensive social care or assessment and treatment unit placements resulting from local services being unable to meet the needs of the individual. A diagnosis of ASD allows for appropriate support and reasonable adjustments to be made.

Benefits of a diagnosis of ASD include:
- Self-understanding: ‘This is why I have always felt different – it is a relief to know’
- Increased confidence and aspirations
- Greater independence
- Better financial and practical support: Such as the Disabled Students Allowance, or employment support for interviews. Some enlightened employers, particularly in the information technology industry, are realising the potential benefits of employing those with ASD

**Services for people with ASD**

There are examples of excellent secondary care services in different parts of the UK that provide both diagnostic pathways for adults suspected of having autism and also ongoing support to patients. Some of these are detailed in the Think Autism strategy document (HM Government, 2014) and signposted in the RCGP ASD Toolkit (RCGP, 2015).

However, there are significant differences in the availability of specialist services to support GPs in both assessments for a diagnosis and on-going support for people with ASD (Public Health England, 2014). This is despite a raft of recent guidance and legislation to try to ensure that appropriate services are in place (Box 2).

**Box 2. Current autism legislation and guidance.**

- Autism Act 2009 (England)
- Autism Strategy 2008 (Wales), 2010 and 2014 (England), 2011 (Scotland) 2013 (NI)
- NICE CG 128 (2011): Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum
- NICE CG 142 (2012): Autism in adults: Diagnosis and management
- NICE CG 170 (2013): Autism: The management and support of children and young people on the autism spectrum
- Statutory guidance for local authorities and NHS organizations to support implementation of the adult autism strategy (2015)

Recent guidance from the National Institute for Health and Care Excellence (NICE, 2012) is summarised in Box 3. This guidance specifies the services that patients can expect from the NHS. If services for diagnosis and on-going management of adults with ASD are not available in your local area, it is appropriate to request out-of-area referral.

**Epidemiology**

Autism affects 1.1% of the UK population (Baird et al., 2006). Initially, it was thought to predominantly affect males, with early estimates of a nine-to-one male-to-female ratio. This is thought not to be due to women being less likely to have ASD, but rather a result of them being better at hiding their difficulties and ‘fitting in’ with society’s expectations. With increasing awareness of ASD, that ratio is now nearer four to one (Baird et al., 2006) and is likely to drop further in future.

**Clinical features**

**Spectrum of abilities**

‘If you’ve met one person with autism, you’ve met one person with autism’  
Dr Stephen Shore (The-art-of-autism.com)

Autism is a spectrum condition, which means that people with autism have very different abilities and challenges to one another. Many people on the
Communication difficulties

The differences in communication seen with ASD affect both verbal and non-verbal communication. Patients with ASD can be painfully direct and truthful. The individual with autism may find it difficult to understand what is meant if clear and precise language is not used. Jokes, metaphors or sarcasm can be confusing, and this may mean the individual will take what you say completely literally. There are often problems starting, maintaining and ending a conversation with a failure to pick up non-verbal clues that someone else wants to speak – or, in the GP surgery, that the consultation is over.

There is poor recognition of body language. Eye contact is often described as atypical and may be absent, so it appears the person with ASD is not listening, or it may be intense and inappropriate. Facial recognition is sometimes impaired, meaning a person with ASD may not realise that he or she has met you before unless there is some other clue – such as your name on the door. Facial expressions may not mirror the words that are being said so, for example, a person with ASD may smile while discussing bad news, or look angry for no apparent reason.

Understanding and predicting emotions may be impaired, or understanding the perspectives of others. Patients with ASD may be vulnerable to exploitation, as they may have problems differentiating fact from fiction, or recognising that others think differently. Lack of empathy is not a core feature of autism, and many people with ASD will have empathy, although they may find it difficult to express it.

Processing difficulties and rigid or repetitive behaviour

The difficulty that patients with ASD have in processing information can result in the individual focusing on one or two intense interests – often avoiding social interaction. Slow processing may also affect verbal communication. For example, it may take an apparently long time to get the answer to a question while the person processes the information and works on the answer.

Patients with ASD also have rituals or routines; breaking these can be very stressful. For example, if an individual always leaves home at the same time, follows the same route, or always flushes the toilet twice there can be significant anxiety or anger if the routine is broken. There may also be verbal rituals, for example, certain phrases that must be said whenever greeting someone, or dietary rituals with food having to be presented in specific ways, with specific texture or colour.

Motor mannerisms or repetitive actions are often used to calm anxiety (or stimulate). The phrase ‘stimming’ has been adopted to describe them. These are often rapid hand movements, finger flapping, twirling or rocking.

Some people with autism can be under- or over-sensitive to sensory experiences. When any of us experience sensory overload we become more stressed; imagine the difficulties for someone in whom sudden or loud noises cause profound anxiety and there is a fire alarm test. All the senses may be affected so the problems can include sensitivity to strong smells, discomfort from clothes or excessive irritation from the labels in clothes.
Challenging behaviour

The term ‘challenging behaviour’ is used to describe a constellation of behaviours that frequently occur in people with developmental disorders, including autism, but are less usual in other populations. These behaviours include:

- Self-injury
- Severe levels of habitual behaviours, such as rocking or head-banging
- Aggression towards others
- Destruction of property, and
- Verbal aggression

In the past it was considered that challenging behaviour was ‘a part of autism’ by many professionals and that there was nothing that could be done to alter this behaviour. However, it is now clear that challenging behaviours are often the result of poor or inappropriate support, not tailored to the individual’s needs. They occur when someone has problems understanding what is happening around them or communicating what they need. Also, they may occur as a result of underlying medical issues, such as pain or anxiety that have not been recognised and appropriately managed.

An ‘autistic meltdown’ (Ryan, 2010) will most commonly occur when the person becomes very anxious. The meltdown will be different in each person; some may retreat into their own world and refuse to interact whereas others may resort to increasing stimming with rapid finger movements, rocking or foot tapping. For most people, it is possible to predict the situation in which a meltdown may occur, and thus avoid this situation by making reasonable adjustments.

Autistic fatigue

The ability to ‘fit in’ can be learned. Many adults with ASD who are in employment describe autistic fatigue, whereby the energy required to cope with the day at work leads to exhaustion and an inability to undertake other tasks, or social engagements (Slavin, 2013). Therefore, excessive tiredness and fatigue may be a presenting feature of ASD.

Family history

Patients with ASD are more likely to have siblings with ASD. This suggests that there is a genetic basis for ASD and at least 1000 genes have been identified in many different combinations that may contribute to the ASD clinical picture (Geschwind, 2008). However twin studies suggest there may be a combination of genetic and, as yet unidentified, environmental triggers.

Association with other conditions

The link between autism and other co-morbid conditions is complex. The phrase ‘Autism plus’ describes autism with co-occurring other conditions (Gilberg & Fernell, 2014).

Although only a third of those on the autism spectrum will have an additional intellectual disability (MacKay, Boyle, & Connolly, 2016), there is a particularly strong association of ASD with other neurodevelopmental conditions. For example, NICE (2008) stresses the link between ASD and attention deficit hyperactivity disorder (ADHD). Other neurodevelopmental disorders associated with ASD are listed in Box 4.

Box 4. Neurodevelopmental conditions associated with ASD.

- ADHD
- Tourette’s syndrome
- Dyspraxia
- Down’s syndrome
- Tuberous sclerosis
- Cerebral palsy
- Muscular dystrophy
- Fragile X syndrome

In people with a diagnosis of ASD, there is also an increased incidence of: epilepsy (26%) (Viscidi et al., 2013); anxiety and depression (70%) (Siminoff et al., 2008); and gastrointestinal problems (McElhanon, McCracken, & Karpen, 2014).

The latter are difficult to quantify and seem to range from inflammatory bowel disease, through coeliac disease and chronic diarrhoea, to constipation of unknown aetiology.

This means that it is important to bear a diagnosis of ASD in mind for patients presenting with other conditions. For example, a patient with ASD may present with abdominal symptoms and anxiety that have been present for many years.

In utero factors

A recent paper identified higher levels of testosterone and cortisol in the amniotic fluid of mothers who are subsequently found to have children with autism (Baron-Cohen et al., 2015). Other in utero factors associated with ASD are listed in Box 5. It is not clear how
useful the identification of these environmental triggers will prove to be.

**Box 5. Factors in pregnancy that increase the risk of ASD in the infant.**
- Prematurity of under 35 weeks gestation
- Sodium valproate use
- Parental schizophrenia or affective disorder

**Environmental factors**

There has been a lot of interest in environmental triggers for ASD. In 1998, a paper was published in *The Lancet* that claimed an association between the measles, mumps and rubella (MMR) vaccination and subsequent development of autism (Wakefield et al., 1998). This had a dramatic effect on the uptake of MMR vaccination for children, even though the link between MMR and ASD was subsequently disproved and the article in *The Lancet* was redacted (Deer, 2011).

**Premature mortality**

A recent piece of research (Hirvikoski et al., 2016) has highlighted the risk of premature mortality for adults with autism. The average age of death for those individuals with autism and no intellectual disability is 16 years younger than the rest of the population and 30 years younger for those with autism and an intellectual disability. The cause of this effect is likely to be multifactorial, but problems accessing healthcare may be implicated.

**Presentation of ASD in adults**

Although a diagnosis of ASD is increasingly likely to be made in childhood, a significant number of adults may not have been diagnosed. All primary care clinicians need to be in a position to recognise and refer adults with suspected autism. Adults with autism are often marginalised by society; they are vulnerable to poor quality care because their difficulties may not be recognised, either by themselves or by the health services that should be meeting their needs (Barnard, Harvey, Potter, & Prior, 2001).

**Case study 1.**

Anita is 25 years of age and in her first year at university. She has been flagged by the reception staff at the surgery because of her verbally aggressive behaviour. In her exams at the end of her first year she simply wrote that she was going to kill herself and left the busy exam hall. The university authorities arranged an appointment for her with the GP that evening.

Consider a diagnosis of ASD if:
- There are persistent difficulties in social interaction and communication
- There are stereotypic (rigid and repetitive) behaviors, resistance to change, or restricted interests

As ASD is a life-long neurodevelopmental condition the problems will have persisted from childhood and there will often be:
- Poor educational outcomes
- History of bullying
- Problems in obtaining or sustaining employment
- Difficulties in initiating or sustaining social relationships
- Current or past contact with mental health or learning disability services
- Sensory sensitivities

**Assessment of patients with suspected ASD**

**Case study 1 (continued).**

When you assess Anita, you find out that this is her third attempt at higher education. Anita has two very successful siblings, both of whom went to good universities and now have well-paid jobs, but she feels that she has struggled academically all her life. She collects and restores old radios as a hobby.

When challenged about her behaviour with reception staff, Anita said that she found it very difficult to understand the process of making and then keeping an appointment at the surgery and got angry with the staff when she could not achieve her stated aim. Initial assessment confirmed significant anxiety and low mood but also a life-long problem with social situations.

Assessment tools may help GPs to identify patients with ASD. NICE (2012) recommends the Autism Research Centre AQ10. This is a 10-question screening tool that can indicate the need for further diagnostic assessment. This can be used in the GP surgery within a 10-minute consultation. A score of six or more raises the suspicion of ASD, and suggests that specialist referral for further, more detailed, testing is appropriate. However, a lower score should not preclude referral if there is a strong clinical suspicion, on the basis of history and behavioural observation, that a patient has ASD.
Case study 1 (continued).

After referral to a specialist team for a diagnostic assessment, Anita received a diagnosis of ASD. She felt that this made complete sense of her life. She was awarded the disabled student allowance, got a learning skills mentor and a social skills mentor. In her words ‘this turned her life around’ and she is confident that the future looks much better. Her only regret is that it took so long to get a diagnosis and she remains quite angry with her parents for not understanding her difficulties.

Management in primary care

Reasonable adjustments

For patients with ASD to have equality of access to primary care services, it is necessary for practices to make adjustments so that they are ‘autism friendly’. Box 6 lists adjustments that can be made in GP practices to help patients with ASD use their services.

Box 6. Reasonable adjustments.

- Make early or late appointments
- Making longer appointments
- Provide a quiet place to wait, or allow them to wait outside
- Maintain continuity of care when possible
- Provide different ways of making an appointment, such as online or by email
- Nominate a key contact person at the surgery to navigate the system
- Ensure these reasonable adjustments are clearly flagged on the computer system

See www.rcgp.org.uk/asd for further information
The National Autistic Society has further information available on ‘Making your practice autism friendly’ see National Autistic Society (2013)

Consultation techniques should be adjusted for our patients with autism to allow for communication and processing difficulties (Box 7). In particular, it is important to allow time and opportunity for patients to express themselves and to clarify that a clear mutual understanding has been gained.

Medication management

We can encourage compliance with medication using all appropriate aids and we need to realise that medication switches on the grounds of cost, encouraged by medicines management teams, can be a problem for patients with autism. If the tablet is usually yellow, then a red tablet will not be the same irrespective of what we say. When we carry out a medication review, we can consider the appropriateness of continuing with the current regime, and particularly antipsychotic treatment. Also if we continue antipsychotic treatment, then ensure that all appropriate monitoring is taking place in line with current guidelines.

Health promotion and chronic disease management

As a result of communication issues, people with ASD may not find it easy to access routine preventive care, such as screening programmes, or chronic disease management clinics. Opportunistic checks (and vaccination) when the person attends the GP surgery for other reasons may be helpful.

Sudden death in epilepsy is a well-recognised cause of early death amongst people with ASD. Therefore, it is particularly important for patients with ASD and epilepsy to refer early for specialist support if seizure control is poor.

Challenging behaviour

NICE (2012) is clear that the assessment of challenging behaviour should be comprehensive and must evaluate all factors that may act as a trigger to the behaviour. A multidisciplinary approach is essential and assessment should include:

- The physical environment
- The social environment
- Co-existing mental or physical disorders, and
- Communication problems

Sometimes, there is a clearly identifiable cause for challenging behaviour. Examples may be physical discomfort,
such as pain or itching, or additional stress, as might be caused by the absence of a usual carer. If a clear cause is found, then steps should be taken to rectify, where possible, the reasons for the individual’s distress.

If there is no clear and easily reversible cause for the person’s challenging behaviour, positive behavioural support (PBA) should be offered. PBA is a behaviour management system that seeks to identify what the individual is gaining from the challenging behaviour, and what elements of the environment are reinforcing that behaviour. Support is then adjusted to alter these factors.

Antipsychotic medication should be reserved for those individuals in whom the behaviour is so challenging that it renders psychosocial help ineffective until greater control has been gained. Prescribing should be initiated by a specialist, and if it is being transferred to primary care, there should be a clear plan describing the intended duration of treatment and how it will be stopped.

Advocacy and support
People with autism may face exclusion in many areas of society, including employment, travel, social support and education. The benefits system is poor at recognising the limitations of ASD; a person with ASD can ride on a bus, but it does not mean that he or she will ride on a bus without support. However, people with ASD will often answer such questions completely literally, and thus be disadvantaged by the system. GPs may need to act as advocates for patients with ASD, to ensure that they receive the support from society that they need.

There have been several high-profile campaigns, most notably from the National Autistic Society in the UK, asking society to recognise neurodiversity and accept the strengths of those on the autistic spectrum. ‘Difference not indifference’ was their campaign slogan for several years, and they are currently running ‘Too much information’ to try and improve the public’s understanding of the impact of autism for the person and their family.

NICE (2012) emphasises the need for healthcare professionals to signpost patients and their families/carers to sources of support in the community. Carers should be placed on the practice carers register, and information provided about local and national organisations that can offer help.

Key points
- ASD may be associated with other neurodevelopmental, psychiatric and medical conditions
- Diagnosis may be delayed into adulthood
- There is no available treatment for the core features of autism
- ASD is challenging for general practice, due to the wide spectrum of presentation, range of abilities and difficulties with communication
- ASD is associated with premature mortality

References and further information
- HM Government. (2014). Think autism: Fulfilling and rewarding lives, the strategy for adults with

The special needs and autism project (SNAP).

The British Journal of Psychiatry.

American Psychiatric Association.

Autism Research Centre.

Department of Health.

Geschwind, D. H.

Gilberg, C.

Hirvikoski, T.

HM Government.

The special needs and autism project (SNAP).

The British Journal of Psychiatry.

American Psychiatric Association.

Autism Research Centre.

Department of Health.

Geschwind, D. H.

Gilberg, C.

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