



Introduction

This leaflet is designed to help staff who work in general practice to understand and to help patients on the autism spectrum.

What is autism?

Autism is a lifelong, developmental disorder that affects just over 1 in 100 people. Autism affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

Individuals on the autism spectrum vary enormously from each other but they all share the two 'core' features of autism:

- persistent difficulties with social communication and social interaction. For example, they may find it hard to begin or carry on a conversation, they may not understand social rules such as how far to stand from somebody else, or they may find it difficult to make friends
- restricted, repetitive patterns of behaviour, interests, or activities. For example, they may develop an overwhelming interest in something, they may follow inflexible routines or rituals, they may make repetitive body movements, or they may be hypersensitive to certain sounds.

Causes of autism

Autism has a variety of causes, which are likely to be a complex mix of genetic and environmental factors which affect different parts of the brain. Autism is not caused by bad parenting or the MMR vaccine.

Types of autism

Autism is an umbrella term used to describe any form of autism spectrum disorder. You may also come across terms that have been used historically like autistic disorder, Asperger syndrome or PDD NOS. There are many READ codes (clinical terms) in use but we are encouraging the use of a limited number to improve data collection.

Level of functioning

Some people on the autism spectrum have a non-verbal IQ of 70 or more, while other people have a non-verbal IQ lower than 70 (and may also be non-verbal or have very limited speech). Some individuals classified as having 'severe' autism may be highly intelligent and can function very well with the right kind of support. Some individuals classified as having less severe autism, on the other hand, may face considerable difficulties which are overlooked because they appear to be coping.

Uneven profile of abilities

Many people on the autism spectrum have an uneven profile of abilities. This means that they may be very good at certain things (for example, social interaction), but may not be very good at other things (for example, thinking flexibly). Or, even more confusingly, they may have different abilities in the same area (such as good long-term memory but poor short-term memory).

What problems do people on the autism spectrum face?

People on the autism spectrum face many difficulties on a day to day basis. For example, they may find it difficult to understand what someone means if that person doesn't use clear and precise language or if they are not given plenty of time to process what is being said. Or they may become extremely anxious if they are asked to talk to someone they have not met before.

Many people on the autism spectrum will find your surgery a confusing and intimidating place, especially if they have not been there before or if they had an unpleasant experience on a previous visit. (You can find advice on how to make your surgery more autism friendly on the back page of this leaflet).

Co morbidities

People on the autism spectrum are likely to experience the same medical problems as everybody else. However they are also significantly more likely to have one or more co morbidities including:

- genetic conditions such as Fragile X and tuberous sclerosis
- physical disorders such as epilepsy and gastro-intestinal problems
- developmental disabilities such as ADHD and cerebral palsy
- motor skill problems such as a clumsy walk and difficulty balancing
- sensory sensitivities such as hypo-sensitivity to pain and hyper-sensitivity to bright lights
- mental health problems such as anxiety and depression
- cognitive problems including difficulties planning actions and understanding how other people think and feel
- difficulties with a range of functional skills such as sleeping or travelling independently.

Challenging behaviours

Some people on the autism spectrum have challenging behaviours. These are sometimes defined as: 'Culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities'

In the past challenging behaviours were considered to be 'a part of autism'. However it is now clear that challenging behaviours

- are often caused as much by the way someone is supported - or not supported - as by their autism. That support should be flexible and personalised to the needs and circumstances of the individual and their family
- often occur when someone has problems understanding what is happening around them or communicating what they want or need
- may occur as the result of underlying medical issues, such as abdominal pain; mental health problems, such as anxiety; or sensory sensitivities, such as a dislike of strong smells.

Relatives and carers

Relatives and carers of autistic people also face many issues and challenges on a day to day basis. For example, many of them become worried and exhausted looking after someone on the autism spectrum. And they face the frustration of trying to find accurate information about interventions which work or of trying to cope with the lack of adequate services.

The Role of the GP

GPs and other practice staff have a key role in ensuring that patients on the autism spectrum (and any carers) have equitable access to health care. They also have an important role in signposting relevant services and resources and in highlighting the latest evidence-based practice.

Diagnosis

There is no specific biomarker or diagnostic test for autism. Diagnosis is made on the basis of the presence of characteristic behaviours. (Please bear in mind that some female patients may not present in the same way as male patients. For example, they may appear to be more sociable and they are more likely to have been misdiagnosed with another condition, such as obsessive compulsive disorder.) If you suspect that someone may be on the autism spectrum and they do not have a diagnosis you should consider a referral to the local diagnostic team.

As with any condition, diagnosis should be done with sensitivity as some people may be unwilling or unable to accept that they could be on the autism spectrum. However research shows that most autistic adults are relieved to get a formal diagnosis as it can help them to understand themselves better and it can be the gateway to statutory services and benefits.

Post diagnostic support

The local autism programme board and the CCG should ensure the commissioning of local services that offer a package of coordinated care and support - which may include health, social care, housing, educational and employment services.

Treatments and therapies

There is no cure for autism but there are some interventions which can help with some of the problems and challenges faced by people on the autism spectrum.

Physical problems

In most cases, the treatment for the medical problems encountered by people on the autism spectrum is exactly the same as it is for anyone with that medical problem. So, for example, if a patient on the autism spectrum has a physical disorder such as asthma they should be treated in the same way as everybody else.

Mental health problems

In most cases the treatment for the mental health problems encountered by people on the autism spectrum is similar to the treatment for other people, except that it may need to be adapted to meet the specific needs of the individual. So, for example, NICE recommends that CBT for the treatment of anxiety may need to be adapted for autistic people using 'a more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and 'tool boxes')'.

Other problems

There are numerous other interventions designed to help people on the autism spectrum deal with a wide variety of issues. Those interventions include behavioural techniques, medications, augmentative and alternative communication, assistive and adaptive technology, diets and supplements etc. Unfortunately there is still a lack of high quality research evidence to support most of these interventions, although that does not necessarily mean they do not work. Regrettably some interventions are also scientifically unfeasible, potentially harmful or both. For these reasons you should only use reliable sources of information (such as NICE, RCGP and Research Autism — all of which are accredited to the NHS Information Standard).

Making the most of a visit to the surgery

There are a number of simple steps you can take to make it easier for patients on the autism spectrum to visit your surgery.

- make sure their diagnosis is coded as a significant active problem on the records
- make sure their carers are on the carers register if appropriate
- highlight any reasonable adjustments that are needed to allow the patients or their carers to access services - see the section below
- make sure these adjustments are clearly "flagged" on the records
- if someone is registering at the practice and they are anxious about visits, arrange some time to visit without an appointment and when no interventions are needed
- encourage them to use a patient passport and take it to appointments in case they see a member of staff who does not know them
- if they do not understand something – encourage them to say so
- if you refer them to hospital or to another secondary service for tests or treatment write on the referral letter the reasonable adjustments they will need.

Reasonable adjustments

- be prepared to make early/late appointments or longer appointments
- provide somewhere quiet to wait or allow someone to wait outside and then call them in
- allow them to see the same clinician if at all possible (recognising that in an emergency this may not be possible)
- nominate a key named contact person who will navigate the system, this may be a receptionist, administrator or nurse and not necessarily the GP
- provide alternative ways of booking appointments, such as on-line, that do not involve the telephone
- explain at the beginning of the consultation what will happen and how long it should take
- recap and write down the key points at the end of the consultation for them to take away
- provide accessible information in a format they understand about how and when appointments are available and how to get prescriptions or access services like cancer-screening tests.

Further information and additional resources

- www.rcgp.org.uk/clinical-and-research/clinical-resources/autistic-spectrum-disorder.aspx
- www.researchautism.net/primary-care

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