



May 16

Dear Colleagues

Autistic Spectrum Disorders: a clinical priority

The Royal College of General Practitioners has great pleasure in enclosing the Autism Patient Charter. The Charter provides a framework for making GP surgeries more visibly friendly for those on the autistic spectrum and we hope that you will find it of benefit to your practice and consider displaying it both in your waiting room and on your website.

To support your practice in delivering on the commitments in the Charter and in offering services to those with autism, their families and carers, we have included a number of helpful resources developed by the RCGP and partners in this pack. This includes:

- Making the most of your visit to the GP: a guide for those on the autistic spectrum
- Autism and general practice: a guide for primary healthcare professionals
- Top tips for clinicians consulting with patients on the autistic spectrum

These resources have been produced as part of the College's three-year Clinical Priority programme on autism and should support colleagues in the implementation of the Adult Autism Strategy. For more information on this work and for tools to support your practice, please visit: www.rcgp.org.uk/ASD.

Similarly, to access the recently launched ASD eLearning module and update your CPD in this area, please visit: www.elearning.rcgp.org.uk/autism.

Alongside developing resources to support good practice, the College is collaborating with colleagues across primary and secondary care to improve diagnostic service and post-diagnostic support for patients with autism.

Finally, to help improve our knowledge of autism, we are also pleased to include information from the University of Newcastle, which is currently recruiting to its large-scale studies on autism. Please do direct those of your patients affected by autism to the studies so that they can consider volunteering to take part.

If you would like further information on the College's work on autism or have a query about any of the information in this pack, please email circ@rcgp.org.uk or call 020 3188 7598.

Yours faithfully,

Dr Carole Buckley

RCGP Clinical Champion for Autistic Spectrum Disorders
GP in Bristol

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Royal College of
General Practitioners



The RCGP Autism Patient Charter

The RCGP has worked with the Autism Alliance UK to produce this patient charter. It serves to provide a framework for making GP surgeries more 'autism-friendly'.

We want to offer people who have autism the highest quality of care and support. Therefore, if and when you want us to, we will:

- **Staff awareness:** ensure all surgery staff are more 'autism aware' through access to the provision of guidance
- **Environment:** work with people with autism to develop an autism-friendly environment, responding proactively to suggestions people with autism may have
- **Identification/disclosure:** make reasonable adjustments should staff suspect a patient or carer has autism, creating an environment where people feel comfortable disclosing their condition should they wish to
- **Communication and customer service:** ensure staff are aware of the different ways people with autism may choose to communicate, and will try to communicate by the most appropriate means for the individual concerned
- **Challenging behaviour and meltdowns:** make staff aware of the likely causes of challenging behaviour and how to communicate effectively with someone in distress

We also invite your ideas and suggestions as to how we can improve the care and support that we deliver to you, the people who are important to you and others in similar situations.

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/ASD
- www.researchautism.net/primary-care

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Top Tips for Clinicians consulting with patients on the Autistic Spectrum

- Speak calmly and clearly in short sentences
- Ask direct and closed questions – avoid too many choices or too much information in one go
- Wait for responses to questions. Do not repeat yourself or ask in a different way
- No eye contact does not mean the person is not listening. Start a question by addressing them so they know you are speaking to them
- Language should be kept as literal as possible – jokes, metaphors or sarcasm can be confusing
- Check that the person really understands what you have said – the verbal skills or apparent agreement may not mirror actual understanding of the information

- Explain verbally and/or in writing the process of the consultation
- Demonstrate an action or intended procedure before starting it
- Recap and write down future plans. Try to give written information if possible
- Avoid diagnostic overshadowing. Co-morbidity is common and you should always consider a serious illness, particularly if the person's behavior changes.

- Consult family or carers, with permission, for more information and to establish if your patient has particular sensitivities
- But do not assume the person with Autism must have a carer present – they should be offered the same confidentiality as all

- Make sure the diagnosis is coded as a significant active problem on the computer
- Ensure reasonable adjustments needed to access your services are clearly recorded
- Referrals to other services should include clear instructions about any reasonable adjustments that may be needed

Disclaimer

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Royal College of
General Practitioners

Making the most of a visit to your GP: a guide for those on the Autistic Spectrum

If you or someone you are caring for has autism there are some simple steps you can take to make it easier to access your GP:

- You should make sure the diagnosis is coded as a significant active problem on the records
- You should make sure you are on the carers register if appropriate
- You should highlight any reasonable adjustments that are needed to allow you to access the services
- You should make sure these adjustments are clearly “flagged” on the records.
- If you are registering at a new practice and you/your relative are anxious about visits, arrange some time to visit without an appointment and when no interventions are needed
- Use a patient passport and take it to appointments in case you see a doctor/nurse who does not know you: www.autism.org.uk/about/health/hospital-passport
- If you do not understand something – say so
- If you are being referred to hospital for tests or investigations ask them to write on the referral letter the reasonable adjustments you will need at the hospital

Reasonable adjustments might include:

- Early or late appointments
- Longer appointments
- Somewhere quiet to wait
- Or waiting outside and being called in from there
- Seeing the same clinician if at all possible (recognising that in an emergency this may not be possible)
- A key named contact person who will navigate the system for you – this may be a receptionist, administrator or nurse and not necessarily your doctor
- Alternative ways of booking appointments – such as on-line that do not involve the telephone
- Accessible information in a format you understand about how and when appointments are available and how to get prescriptions or access services like cancer-screening tests.



ASD-UK and ASC-UK
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Dear Colleagues,

At Newcastle University we work in partnership with organisations across the UK to recruit to two national autism spectrum research projects that have NHS Ethical approval. **Please consider letting adults on the autism spectrum, relatives of adults on the spectrum, and parents of children know about our national research.**

We have included information about each study, and an A4 poster - we'd be grateful if you would consider putting this on your practice noticeboard. Copies of study materials are available through the links below. These can be printed for potential participants, or we can send you copies.

**Study 1: Adult Autism Spectrum Cohort – UK
(for adults on the autism spectrum, and for relatives of adults)**

ASC-UK is a research project that aims to learn much more about the life experiences of both adults with an autism spectrum disorder and relatives of adults.

Study documents can be downloaded, or you can email and we'll send you printed versions:

<http://research.ncl.ac.uk/adultautismspectrum>
adultautismspectrum@ncl.ac.uk

**Study 2: Autism Spectrum Database UK
(for parents of children on the autism spectrum)**

The **Autism Spectrum Database UK** (ASD-UK) gathers data from parents about children on the autism spectrum, gives families the opportunity to take part in research, and helps researchers recruit families and children to high quality UK ASD research studies.

Study documents can be downloaded, or you can email and we'll you send printed versions:

www.asd-uk.com
asd-uk@ncl.ac.uk

Thank you for considering supporting recruitment to these national research projects that are helping us understand more about the autism spectrum across the lifecourse.

Best wishes,

Dr Jeremy Parr, Consultant/Clinical Senior Lecturer
Newcastle University, UK

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We are recruiting to 2 exciting national autism research studies!

Study 1

Adults on the autism spectrum *and* Relatives and carers

This project is about understanding how adults & relatives' lives change over time

We are recruiting:

- Adults on the autism spectrum
- Relatives and carers of adults on the autism spectrum
 - 16+, any ability, diagnosis not essential

Visit: www.autismspectrum-uk.com/ to join online

To receive information by post please contact us at:

Email: adultautismspectrum@ncl.ac.uk

Phone: 0191 282 1380



Study 2

Parents of children on the autism spectrum

ASD-UK is a UK research family database of children on the autism spectrum. The aim is to provide accurate data and give families the opportunity to take part in research studies

Visit: <http://asd-uk.com/> to join online

To receive information by post please contact us at:

Email: asd-uk@ncl.ac.uk

Phone: 0191 282 1380

