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## How to do it: the neurological consultation with an autistic patient

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The authors have a range of experiences of autism in various settings. TB has lived experience of autism as well as being an autism researcher and PhD student, and has experience of teaching autistic adolescents. NH is the parent of an autistic adult. MC and KG work in clinical neurodevelopmental / community paediatric services. KL and CJ research autism and other neurodevelopmental conditions. TM is a clinical academic Fellow in neurology.

### Abstract

Autism is a neurodevelopmental condition with a very heterogeneous presentation. Autistic people are more likely to have unmet healthcare needs, making it essential that healthcare professionals are 'autism-aware'. In this article, we provide an overview of how autism presents and use case studies to illustrate how a neurological consultation in an outpatient clinic environment could prove challenging for an autistic person. We suggest how to improve communication with autistic patients in clinic, and highlight the importance of a patient-centred and flexible approach.

### Introduction

Autism spectrum disorder (ASD) is a common, heterogeneous, strongly heritable neurodevelopmental condition that first presents in early childhood and persists throughout life (1). Its prevalence is approximately 1.5% in developed countries (2), with more males affected than females (ratio of 3:1, (3)). It is defined by a persistent pattern of social communication difficulties and differences, as well as the presence of restricted, repetitive behaviours (Box 1, and (4)). These mean that autistic people can find it difficult to understand the meaning and intentions of others and to understand social rules. Their communication style can appear awkward or stilted, they can find it hard to make and sustain friendships, and they may be singled out or bullied. Autistic people may fixate on detail and struggle to see the wider context. They may also have intense, overwhelming interests, a need for routine or rituals, or struggle to adapt flexibly to a change of plan. Hyper- or hypo-sensitivities in different sensory modalities are often present, sometimes leading to behaviours that are sensation avoidant or sensation seeking. The core features of autism can manifest very differently between individuals (Box 1, and (5)), and there also tend to be qualitative differences in how autism presents between the genders (6). It may not be apparent that someone is autistic, and individuals may try to camouflage their symptoms to try to conform to neurotypical social norms, something that typically requires intense practice and effort (7).

Box 1. Clinical features of autism

Diagnostic criteria for ASD (4) can be fulfilled by many different presentations and symptom combinations. Autistic people can also have significant intellectual disabilities or have normal or high IQ, but an autistic person's cognitive abilities do not necessarily correlate with their ability to function on a day-to-day basis.

Some broad examples of how social communication difficulties can present in autistic individuals (5):

- **An active but unusual social style**, where there is an interest in social interaction but the communication style is qualitatively unusual. Social interactions are initiated but are typically on the person's own terms.
- **A passive social style**, where there is an interest in social interactions but awkwardness and uncertainty about how to behave. Social interactions are not initiated but responses to others are made.
- **An aloof social style**, where social contact is avoided. There is an absence of initiating or responding to social interactions.

Some examples of restricted and repetitive behaviours:

- **Repetitive or unusual use of language**, for example using overly formal wording or stereotyped phrases
- **Obsessional interests**, either in unusual topics / pursuits or in more mainstream ones
- **Intense need for routine** and limited ability to cope with change
- **Stereotyped motor mannerisms** such as hand flapping
- **Sensory hypersensitivities** such as intolerance to sounds, lights or touch
- **Unusual sensory interest** in aspects of the environment, leading to sensory seeking behaviour, such as staring at lights, or sniffing, licking or stroking objects

Rates of other neurodevelopmental conditions such as intellectual disability (8) and attention-deficit hyperactivity disorder (ADHD, 9), and of mental health problems, especially anxiety and depression, (10,11) are higher in autistic people than in neurotypical people. A notable study found the comorbidity rate of any psychiatric condition (including ADHD) in autistic children to be 70% (10). Around 30% of autistic individuals have intellectual disability (8); for advice on how to consult with people with intellectual disability, we direct readers to Bradley et al (12).

Of specific relevance to neurologists, rates of autism in children with epilepsy are around 20% (13), and rates of epilepsy are around 20% in autistic individuals with intellectual disability and around 8% in those without (14). However, the broadening of the diagnostic criteria for autism in recent years means actual rates of autism in epilepsy are likely to be higher, and rates of epilepsy in autism lower (15). Rates of other neurological conditions are also increased in autistic individuals, with elevated rates of macrocephaly, hydrocephalus, cerebral palsy, migraine/headache and congenital anomalies of the nervous system compared to neurotypical people (16). Therefore, it is very likely that neurologists will regularly undertake consultations with autistic patients in their practice.

Research has found that autistic adults have healthcare disparities and unmet healthcare needs compared to non-autistic people, including not receiving care for a physical health or mental health problem, and having higher levels of emergency department attendance (17), hence the importance of understanding autism and recognising its potential impact. A qualitative study of autistic adults found that they almost universally requested increased autism training for healthcare providers (18), and we refer readers to this study for a detailed description of their experiences and their

recommendations for improving healthcare. Table 1 gives links to several resources aimed at promoting understanding of autism.

It is important to recognise that some individuals have many features of autism but have not formally sought a diagnosis, and conversely some may have some features of autism but not fulfil the full diagnostic criteria. Regardless of diagnosis, some of these individuals may self-identify as autistic whilst others may have limited insight into their differences. In this article we use four hypothetical case studies to illustrate the wide heterogeneity of autism, showing how it can have an impact at any age. We suggest ways in which a neurological consultation could be facilitated in each case by using a flexible, patient-centred approach that can be applied whether or not a patient has a formal diagnosis of autism.

### A note on terminology

There have been various studies exploring how autistic people and their families prefer to be referred to. The majority view amongst autistic adults is that identity-first language (e.g. autistic person) is preferable to person-first language (e.g. person with autism) (19). However, given the differing views between individuals, it may be appropriate to establish which terminology is preferable to a patient and their family at the outset. It is also important to note that the traditional view that autism is a medical disorder is challenged by the neurodiversity movement, which views autism as a positive identity that does not require medicalisation or curing (20).

### How to approach a consultation with an autistic patient

A summary of adjustments that may be useful throughout the consultation process is provided in Table 2.

#### *General points*

There are various tips for communicating with an autistic person on the National Autistic Society website (21), which are applicable to communication in all settings. To help an autistic person filter out information that is not directly relevant, say less, speak slowly, avoid open-ended questions, and do not ask more than one question at once. Another reason for these modifications is that autistic people often need longer than neurotypical people to process information (22), so allowing enough time for the consultation is key. If known in advance, a longer clinic appointment might be appropriate. Autistic people can interpret things literally (23), so be specific in your choice of words and avoid figures of speech, irony and exaggeration. Autistic people can struggle with interpretation of and use of non-verbal communication such as facial expressions and body language, so reduce reliance on these in your own communication style. Avoid speaking too loudly in case of auditory sensory sensitivities.

In terms of the communication that you may receive from the autistic person, do not necessarily expect them to make small talk or to respond to your questions in a conversational style, although some may be happy to chat. Listen carefully and allow the autistic person to communicate with you in their style. If you can find out someone's interests, this is often a good way to try and engage them at the outset, although some autistic people may then find it difficult to orient away from discussing their strong interests. Autistic people's speech can be of unusual volume or have unusual intonation or reduced variation in tone. They may show reduced or unusual facial expression and body language. Eye contact can feel uncomfortable to autistic people so do not expect an autistic person to look at you directly. Some may rely on a learnt pattern of eye gaze that appears unusual. Such elements of communication style can be confused with presentations of depression or anxiety, and although these

do co-occur highly with autism (10,11,24) these signs should be interpreted carefully. Be aware that an autistic person may say things that could be interpreted as inappropriate or unusually blunt due to difficulties understanding social context. This does not mean that they are intentionally being rude or impolite. Do not take offence to any such occurrences and respond to them sensitively.

Clearly, children and young people will attend appointments with a parent or guardian. As autism is heritable, parents may themselves have communication difficulties. Similarly, autistic adults across the full range of abilities may wish to attend with a family member or carer / other advocate to support their communication needs and help alleviate anxiety, and this should always be facilitated. It is imperative to address, involve and offer explanations to the autistic patient themselves as well as involving the person who has attended with them, even if the patient is non-verbal.

#### *Clinic set-up and environment*

Autistic people often like to know what is going to happen in advance. A standard appointment letter could be adapted to include bullet points explaining what will happen and including photos of the clinic, or an autism-friendly leaflet about your service could be developed. Ensure clinic letters have clear contact details so that there are reliable mechanisms for patients to get in touch at short notice, if needed. Autistic people often prefer routine and predictability, and so appointments not occurring at their scheduled time or being cancelled may cause distress. Consider scheduling clinic appointments when they are less likely to be influenced by factors that cause appointments to run late - for example, the first appointment in a clinic. If an appointment is running late and the patient asks when they will be seen, give a specific time e.g. in ten minutes (and honour this) rather than a vague estimate e.g. in a bit, or not long now – however, it would be helpful to let the patient know that clinic is running late as soon as you are aware.

There are various environmental factors applicable to any medical consultation that an autistic person may find distressing (25). There is a checklist for autism-friendly environments (26) which is endorsed by the National Autistic Society and the National Institute for Health and Care Excellence. Ask the individual if they have any requirements so that these can be accommodated if possible. Ensure these preferences are written in the notes so that the individual does not have to repeat their needs. Overcrowding, noise and harsh lighting can cause problems due to issues with personal space or sensory hypersensitivities. Such factors may cause an autistic person extreme anxiety or cause them to go into a sensory overload and not be able to process information (27), resulting in 'shutdowns' or 'meltdowns'. If this occurs, ensure the staff member supporting the patient remains calm and offers an escape to a quiet space (28). We recognise that pressures on space and resource restrictions may make environmental modifications difficult or impossible, so it is worth making autistic patients aware in advance if this is the case.

#### *Remote consultations*

With the increase in the ubiquity of video-calling platforms, remote methods of consultation have become more commonplace in recent years and have now been rapidly necessitated by the Covid-19 pandemic (their utility in neurology, including discussion around conducting examinations, is reviewed in detail by Duncan and Macleod (29)). This may be preferable for autistic people in some respects, as they do not have to visit the clinic environment, but equally, telephone and video appointments can augment communication challenges. Seek clarification in advance as to which method would be preferable if remote consultations are being offered, and, as for face-to-face clinics, try to adhere to appointment times.

#### *History taking and examination*

There are issues specific to a neurological consultation that may be especially challenging for an autistic person. Be particularly clear and specific in your history taking as concepts in neurology can appear more abstract than those in other specialties. Check the person really understands what you have said. Asking an autistic person an open question such as how they are feeling or how something feels could be difficult for them to answer. Questions such as 'Does your head hurt?' or 'Do you feel tingling in your legs?' are easier to interpret. Some autistic people have a very high pain threshold so might not say that they are in pain despite injury or pathology.

A neurological examination involves more complex instructions and active participation from the patient than some other medical examinations. Explain clearly what each part of the examination involves and why you are doing it. Simple commands are preferable alongside demonstrating actions where necessary. Some may struggle with hypersensitivity and so testing deep tendon reflexes with a tendon hammer, or examining sensation with cotton wool, a pin, or a tuning fork, might cause distress. Showing equipment and demonstrating tests beforehand can help. Ask the patient if they are comfortable with each test. Some autistic people may be intolerant of others being in their personal space (although some may have little concept of others' personal space). Fundoscopy can feel particularly intrusive, and light sensitivity can exacerbate any challenges. It may be worth structuring your examination sequence so that the progression is from the least invasive to the most invasive aspects (30).

Neurological investigations such as CT and MR scans, EEGs, and neurophysiology tests can be challenging for autistic people due to personal space encroachment and noise hypersensitivity. Again, give a clear explanation of what the procedure involves in advance (a video could work for this, for examples see Table 3) and allow extra time for them to settle into the environment of the scanner.

#### *After the consultation*

After a consultation, if referral to other specialties or to allied health professionals is indicated, ask the patient if they would like you to share information about necessary adjustments and considerations so they do not have to repeat themselves. If writing a letter to the patient, as with verbal communication, be clear, specific and unambiguous in the language you use.

Increased autism awareness from all clinic staff and small changes throughout the process can reduce inequalities in care and remove barriers to seeking care.

#### Summary / key points

- The core features of autism manifest very differently between individuals, and it may not be immediately apparent that someone is autistic, if at all
- Autistic patients have a higher prevalence of neurological problems than the non-autistic population
- You will need to adapt your own communication style and alter your expectations of the communication you receive
- There are many adaptations that can be made to the clinic processes and environment to improve the experience and support the wellbeing of autistic people, and the whole multidisciplinary team should be autism-aware
- There are many useful learning resources about autism online

Table 1. Useful resources

Useful resources	
<a href="https://www.autism.org.uk/what-we-do/campaign/public-understanding/too-much-information">https://www.autism.org.uk/what-we-do/campaign/public-understanding/too-much-information</a>	The National Autistic Society's Too Much Information campaign – a series of short videos to increase public understanding of autism
<a href="https://autismwales.org/en/parents-carers/information-for-parents-carers/living-with-autism-film/">https://autismwales.org/en/parents-carers/information-for-parents-carers/living-with-autism-film/</a>	A short film by the Welsh Government's National Autism Team about how the features of autism can impact on an individual's daily life
<a href="http://www.autismchildsigns.com">http://www.autismchildsigns.com</a>	An evidenced-based training film (The Birthday Party) for professionals about the signs of autism in children on the Welsh Government's National Autism Team website. The webpage also has links to the signs of autism across the age range, from pre-school children to adults
<a href="https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/asd-toolkit.aspx">https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/asd-toolkit.aspx</a>	An online 'toolkit' of resources that aims to be a user-friendly guide to autism for primary care professionals, people affected by autism, clinical commissioning groups, as well as interested members of the public

Table 2. Summary of the main adaptations to consider for autistic patients

Summary of the main adaptations to consider for autistic patients	
<b>Before the consultation:</b>	<ul style="list-style-type: none"> <li>• Consider your own training needs and those of your team in terms of autism awareness</li> <li>• Assess whether the clinic environment is autism-friendly</li> <li>• Consider modifying the standard appointment letter or making an autism-friendly leaflet about your service</li> <li>• Consider booking the appointment for a time when clinic is likely to be quieter and less likely to be running late, and keep the patient informed with specific information if it is behind schedule</li> <li>• Consider allowing extra time for the appointment</li> <li>• Find out preferences for remote consultation options in advance if they are being offered</li> </ul>
<b>During the consultation:</b>	<ul style="list-style-type: none"> <li>• Be clear and specific when asking questions</li> <li>• Check the patient understands what you have said</li> <li>• Explain clearly what each part of the examination involves</li> <li>• Show the equipment in advance</li> <li>• Ask the patient if they are comfortable with each stage of the examination going ahead, and only give one instruction at a time</li> </ul>
<b>After the consultation:</b>	<ul style="list-style-type: none"> <li>• If you are making an onward referral, ask the patient if they would like you to share information about their autism in relation to any adjustments that may be needed in future consultations</li> <li>• Keep letters to the patient concise and specific</li> </ul>

Table 3. Examples of videos describing MRI and EEG

Examples of videos describing EEG and MRI	
<a href="https://www.youtube.com/watch?v=rCa-5N3_WXs">https://www.youtube.com/watch?v=rCa-5N3_WXs</a>	A video for children from the What? Why? Children in Hospital Charity explaining what it is like to have an MR scan
<a href="https://www.youtube.com/watch?v=6vtKS-MA5n4">https://www.youtube.com/watch?v=6vtKS-MA5n4</a>	A video from King's College Hospital explaining what it is like to have an MR scan
<a href="https://www.youtube.com/watch?v=TNifQCrluo4">https://www.youtube.com/watch?v=TNifQCrluo4</a>	A video for children from the What? Why? Children in Hospital Charity explaining what it is like to have an EEG
<a href="https://www.youtube.com/watch?v=KXS268XsRic">https://www.youtube.com/watch?v=KXS268XsRic</a>	A short video from the Epilepsy Society explaining what it is like to have an EEG

### Case 1

A 26-year-old woman attends neurology for assessment of frequent headaches, likely to be migraines. She was diagnosed with autism two years ago and has significant social anxiety dating back to her early teens. She tends to respond to questions briefly but affirmatively and agrees with proposed suggestions unquestioningly. However, the neurologist suspects that her anxiety is such that she often nods or says yes, whatever she really thinks, simply to complete an interaction quickly and be allowed to leave social situations. She struggles with eye contact but looks just to the side of others' heads to disguise this. She has been reluctant to disclose her autism diagnosis to people other than her family, who encouraged her to go through the diagnostic process. However she has told her GP, who has mentioned it in the referral letter.

Suggestions to facilitate the consultation:

- Offer her written information on treatment options to take away from clinic and offer her more time to reach decisions, rather than expecting her to reach a conclusion on the spot.
- Suggest she keeps a headache diary at home and bring it to clinic.
- Suggest she might attend with an advocate for future appointments if she wishes. This could also be flagged in advance of the appointment as the GP has mentioned her autism in the referral letter.

### Case 2

A 15-year-old boy known to have mild learning disability and autism has been referred for possible absence epilepsy, although the referrer's clinical suspicion is that this is more likely to be inattentive ADHD. He attends with his mother and father, who, when asked about family history, say that they have both been diagnosed with autism as adults. He is sociable and likes to talk to adults at length about his main interest, which used to be Pokemon but is currently cars. He takes language very literally, and many of the phrases he uses are catchphrases from TV shows, spoken with an American accent. He is not keen to be examined, saying that he does not like people touching him.

Suggestions to facilitate the consultation:

- Engage his full attention before speaking to him. This could be done initially via his interest in cars.



- Explain clearly and simply to him what each stage of the examination entails. For example, he might see and hold the instruments before the doctor uses them, e.g. the reflex hammer or the ophthalmoscope.
- He and his parents may have good insights for managing his tactile sensitivities (e.g. using firm touch and avoiding light or tickling sensations; giving a clear warning before he is touched).
- Keep the communication style clear and direct to all three family members. While his parents have disclosed their autism diagnoses, in general do not assume an autistic child's parents have a neurotypical communication style.

### Case 3

A 55-year-old man, a university professor with no past medical history including no neurodevelopmental diagnoses, is referred to neurology for assessment of a new-onset tremor. He has done a lot of reading on the causes of tremor. He brings to clinic many pages of notes that he has made from research papers. The neurologist starts the consultation with an open question but it rapidly becomes apparent that the patient is fixated on the idea he has Parkinson's disease. He talks in detail about the reading he has done. It is difficult to shift the focus of the consultation back to other relevant aspects of his medical history, as he does not seem to recognise the doctor's social cues. His speech has little variation in tone, and his eye contact varies between intense and avoidant. Having taken the full history and examined him, the neurologist's diagnosis is that he has an essential tremor.

Suggestions to facilitate the consultation:

- His pattern of unusual social communication, which includes propensity to detail, rigidity and lack of response to social cues, suggests that some of the communication strategies used with autistic people might be helpful.
- Switch to closed, direct questions and reduce your reliance on facial expression and body language cues to try to bring back the consultation to the other information you need to gather.
- He will likely need a detailed explanation of the rationale for the diagnosis to unpick his fixation on Parkinson's disease.

### Case 4

A 15-year-old girl with moderate to severe intellectual disability attends the epilepsy clinic. She was diagnosed with autism at age 3 years, and has significant sensory difficulties. She recently had three episodes that may have been focal impaired awareness (complex partial) seizures. The clinic coordinator had sent out a map showing the location of the clinic within the large, busy hospital site, which the family had found very helpful, and the clinic itself is quiet and running to time. However, she had to be weighed and measured unexpectedly and to have her blood pressure checked. She had not done these before and found the sensory aspects challenging. She subsequently became anxious and started flapping her hands and rocking. The neurologist suspects epilepsy based on the clinical history given by her parents, and requests an MR scan of her brain and an EEG.

Suggestions to facilitate the consultation:

- Hand flapping and rocking are ways that an autistic person might self-regulate when anxious. Therefore, clinicians should not try to intervene. However, they could ask her and her parents about the level of distress and whether an intervention might help (e.g. 5 min break in the consultation; allowing her to pace rather than sit).
- Communicate directly with her in a calm and quiet manner and do not rush proceedings. Where appropriate and necessary, facilitate communication with her via her parents.
- When writing her MR scan and EEG referral forms, mention her autism, intellectual disability and sensory processing difficulties so that technician staff are aware in advance. They can then consider ways to meet her additional needs and can offer extra time for the appointments as appropriate.
- MR scanning in particular can be extremely stressful for someone with this patient's profile of difficulties. Direct her and her family to video resources on MR scanning and EEG (Table 3) so that they know what the procedures entail and so can prepare accordingly.

#### Further reading

- Bradley P, Byrne K, Ring HA. How to get the most from a consultation with a person who has a learning disability. *Pract Neurol*. 2012 12(1):44–8
- Duncan C, Macleod AD. Video consultations in ordinary and extraordinary times. *Pract Neurol*. 2020 20(5):396–403

#### Competing interests

MC has spoken about the Cwm Taf Morgannwg Neurodevelopmental Service at conferences hosted by Takeda (formerly Shire) and Flynn Pharma. These talks were not related to the content of this article and MC did not receive personal payment. There are no competing interests for any other author.

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MC and KG wrote the first draft of the manuscript. KL, TB and CJ made major additions. MC, NH, TM and CJ developed and refined the case studies. TM edited the manuscript. All authors approved the final version.

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