Consulting with a patient with autism

Autism spectrum disorder (ASD) is a complex life-long neurodevelopmental disorder that affects 1.1% of the UK population. It is a social communication disorder that is also characterised by rigid and repetitive routines or behaviours, and sensory sensitivities. This makes it a challenge for both the individual and the GP to have a successful consultation. There is also a very uneven profile of abilities, language skills may be limited, non-verbal understanding may be limited, and expectations of the outcome of the consultation may well be different from those of the ‘neuro-typical’ patient. For these reasons, it is important to have the diagnosis of autism clearly marked on the patient records, and for the doctor to adjust his or her consultations skills to suit the person consulting.

Less than 50% of those on the autistic spectrum have an additional intellectual disability, so do not assume that there needs to be a carer or family member present. They should be offered the same confidentiality as all your patients; however, valuable help can be obtained from family or carers if you have the individual’s permission to speak to them. Important information can be gathered about sensory sensitivities, changes in behaviour, and the expectations of what help may be needed. If investigations or treatment are refused, family and carers can be a useful resource to help assess the patient’s level of understanding about this decision. This can be used to underpin a discussion on the mental capacity of the individual who has made that decision.

In the consulting room:

- 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 jump to repeat yourself or ask in a different way without giving the person time to answer
- No eye contact does not mean that the person is not listening. Start a question by addressing the individual so that he or she knows 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 agreement may not mirror actual understanding of the information

It can take several consultations to begin to understand your autistic patient and feel comfortable that you have a mutual understanding of the process and desired outcomes. It is preferable to maintain continuity of care unless an emergency occurs, and if possible allow longer for the consultation. Patients with autism may make little or no eye contact, or may stare intently at you, which can be disconcerting at first. They will consider their answers carefully and may be slow to respond; also they may take what you have said very literally. If possible explain, both verbally and in writing, the process of the consultation. It helps if the practice has taken steps to become ‘autism friendly’ and has clear guidance on the process of making a consultation, what to expect at the surgery, who the staff are – preferably with photographs, and what services are offered. It also helps if the reasonable adjustments the patient needs to access the services are clearly flagged, for example, a quiet place to wait.

Sensory sensitivities can make access to the surgery difficult; the waiting room can be a noisy chaotic place. Your consulting room is probably lit with fluorescent tube lighting and will have a prominent computer screen. When combined with meeting an unfamiliar person and being asked unexpected questions, this will make the autistic patient in front of you very anxious. This may prevent them from speaking to you about the real reason they are with you. It is easy for them to misinterpret your questions, and for you to misinterpret their answers. Additionally, rising levels of anxiety may produce an autistic ‘meltdown’ or behaviour that is challenging to services. This is different in each person. There may be a total shutdown, where the person retreats into his/her own shell and will not move, speak or interact. It may produce ‘stimming’, which is the word used to describe a repetitive body movement that most autistic people have to some extent – often rapid finger movements, or rocking. It may produce aggressive behaviour, a result of the person trying to get away from the anxiety-provoking situation. The aggression may be self-harming, such as striking the head or may be directed at those in the vicinity. If the patient is a child, apparently normal attempts to hold and comfort them can result in a deterioration of their behaviour. The need to escape the stressful situation can be overwhelming, and the only answer may be to abandon the consultation and rebook it.
For this reason, it is very important to have a clear idea of the reasonable adjustments a person needs to be able to access your services without provoking such a potentially catastrophic meltdown. This may mean early or late appointments, letting them wait in their car until called, seeing the same clinician in the same room – or sometimes being even more innovative. I used to consult a young man in our practice garden, that has a soothing water feature and a bench, until he became more used to the premises and agreed to come into my room. Patients with autism need to be encouraged to access the community in a way that is not threatening to them, so home visiting, unless on clinical grounds, should not be expected of you.

Case study 1. Example of a consultation dialogue with a patient presenting because of angina-type chest pain

Doctor: Hello, how are you today?
Patient: I'm ok, thanks.
Doctor: Why have you come?
Patient: My Mum told me to.
Doctor: Why did your Mum tell you to come?
Patient: Something in my chest.
Doctor: You have pain in your chest?
Patient: No.

At the consultation the patient does not have exercise-induced pain and has given a completely literal answer to your question. It is clear that this consultation could be frustrating both for you and the patient – particularly if you are already running late.

The consultation may well be a question and answer session, and when you have established your differential diagnosis it is important to give clear advice, preferably in writing, about future plans. It is also important to demonstrate an action or intended procedure before starting it. Some of those on the autistic spectrum will find it very difficult to tolerate a stranger touching them. For example, the sphygmomanometer cuff may cause actual pain, but with careful preparation it is usually possible to achieve most things. There may have to be some slightly different approaches, and if in doubt, it is worthwhile seeking advice from someone with more experience.

We recently managed to fit a contraceptive implant in a young woman on the autism spectrum by getting her to wear headphones and playing her favourite music, and using a topical lidocaine gel on her arm before starting the procedure. This numbed the arm to touch. However, another young woman on the autism spectrum who needed a minor surgical procedure wanted a detailed account of what was happening and watched the whole process.

The internet has proved an enormously useful tool for many with ASD; there are a host of chat rooms and forums that can be used to research and discuss with like-minded people many aspects of their lives, including health and wellbeing. If you are going to offer a choice of interventions, or medication options, be aware that the autistic patient may want more information than is typical, and may want to take details away to further consider your advice. This is refreshing and the only drawback is the need for another consultation to complete the decision-making process. If possible book this appointment immediately, so that the opportunity to offer a health intervention is not lost. The patient with ASD may be reluctant to repeat the process of making and keeping an appointment with you.

ASD is associated with premature mortality. Although the reasons for this are not yet clear, and will undoubtedly be multifactorial, co-morbid conditions are common: 35% have epilepsy and 70% will have additional mental health needs. It is important to avoid diagnostic overshadowing and not attribute everything to autism. If a person’s behaviour changes then look for the reason for that change, it may be pain, anxiety or depression that all have suitable interventions, unlike the core features of autism for which there is no treatment.

Finally, if you need to make a referral to secondary care services please ensure the reasonable adjustments your patient needs are clearly recorded on the referral letter. Opportunities to offer health care should not be lost because the person cannot tolerate a secondary care setting, which may appear even more chaotic and inflexible than your surgery.

A brief summary of Top Tips for Clinicians Consulting with Patients on the Autistic Spectrum can be downloaded at: www.rcgp.org.uk/asd. The autism toolkit has several useful resources for clinicians, patients and carers and is available free to everyone.

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