



A guide for GPs about mental health and autism



What autistic people would like their GP to know

Mental Health Autism (MHAutism) researchers asked adults diagnosed with autism (without learning disability) and their families, what would make visiting their GP about a mental health difficulty easier? Their stories were used to inform this guide and are available on our website (<http://mhautism.coventry.ac.uk>).

What is autism?

- Autism is characterised by difficulties in socialising and communicating with others effectively, a tendency to have narrow unusual interests and fixed routines, and sensory difficulties¹.
- 1% of people (700,000) in the UK have autism, most of whom are adults².
- Autism without language delay or learning disability is commonly referred to as High Functioning Autism (HFA) or Asperger Syndrome (AS).
- Recent research suggests many people with HFA/AS frequently try to mask or camouflage their symptoms in an attempt to fit in. This means that their struggles can be 'hidden'³.
- A recent study showed the term 'autistic person' is preferred among the autistic community, while 'person with autism' is preferred among professionals. We suggest GPs ask their autistic patients which term they would prefer them to use⁴.

People with autism want the world to be more aware and understanding of autism. We can help by asking autistic people how we can better support and include them.

Mental health in autism

- A majority of people with autism (80%) meet criteria for at least one mental health condition⁵.
- Depression is the most common mental health condition, affecting up to 50% of those with autism⁶.
- Up to 66% of adults with Asperger Syndrome have contemplated suicide at some time in their lives⁷.
- We recommend GPs proactively ask people with autism about their mental health and suicidality.

It is very important to listen when an autistic person tells you they are having thoughts about ending their life, and understand that they need urgent help. We have developed autism friendly safety plans that are available to download from our website (<http://mhautism.coventry.ac.uk>)

GP practices have a legal duty to make reasonable adjustments for autistic adults under the Equality Act 2010. The following recommendations describe what adjustments GPs can make.

How to conduct an autism friendly consultation

- Allow more time. Offer people with autism double appointments.
- Many autistic people have sensory sensitivity that can affect all of their senses. Sensory 'overload' can increase anxiety and stress, but you can help reduce this:
 - Keep lighting low. Fluorescent lighting can be uncomfortable, natural sunlight is ideal.
 - Keep noise to a minimum. Background noise can be distracting. Speak softly and calmly.
 - Keep touch to a minimum. Unexpected touch can be difficult, especially from strangers.

- People with autism respond well to structure and routine. Seeing the same GP, in the same room, in the same format each time alleviates anxiety and will help consultations run smoothly.
- To avoid misunderstandings people with autism have told us that they are happy for GPs to ask them to repeat or summarise what has been discussed and agreed on during the consultation, write down the main points of the meeting for the autistic person to take away with them.
- Provide a quiet space within the surgery where your autistic patients can go and sit quietly for a few minutes if they wish to compose themselves after the consultation before they leave.
- It is difficult for many autistic people to go to their GP and ask for help, asking for help is a social skill they may lack. If GPs know one of their patients has autism they should proactively ask them if they are coping or struggling whenever they see them.
- Autistic people may not be able to visit their GP when they are in crisis, as this will only add to the distress they are experiencing. If they visit you when they feel more able to talk about their experience you may not see the full extent of their crisis. However, what they are reporting should be taken seriously as autistic people are known for telling the truth or 'telling it as it is'.
- Autistic people may not always be able to interpret others facial expressions, or show appropriate facial expressions themselves. When assessing a person with autism GPs should rely more on the words being spoken rather than what their body language is saying.
- GPs need to understand 'masking', a common behaviour experienced among high functioning autistic people. People with autism often mask their symptoms to fit in, pretending everything is fine and that they are coping. Masking so much in everyday life means they may find it difficult to show their feelings fully and admit there is a problem when they go to their GP. Be aware that masking may mean you do not see the full extent of their distress.
- Some people with autism may struggle with self-advocacy, sometimes saying 'yes' to something because they are finding the interaction difficult and just want to leave. If their visits are too stressful they may not go back. If GPs understand this difficulty they can adapt the consultation accordingly.

Autistic people often struggle with mental health difficulties such as depression and anxiety because the world around them is not autism friendly. Mental health difficulties should be treated and not accepted as being part of their autism, as the consequences can be devastating.

- Autistic people may not respond well to open questions. When beginning the consultation instead of asking 'how can I help you?' say 'why have you come to see me today?' When they tell you about an experience instead of asking 'how do you feel about that?' ask 'did that make you feel...' Open questions can be unclear and require interpretation, while closed questions are specific so easier for autistic people to understand exactly what you are asking them so they can respond appropriately.
- Autistic people would like to have a relationship with their GP and see the same GP each time. Often people with autism who experience mental health difficulties have a long history of those difficulties, sometimes starting in childhood. If they are seeing different GPs each time they don't want to have to explain that history in order for you to understand why they have come to surgery. Practices could organise a group where autistic people can come and meet their GP so they can start building a relationship.

- When a person receives a diagnosis of autism it would help if their GP could offer them an information sheet explaining their diagnosis, with a list of 'do's', 'don'ts' and strategies for family, friends or caregivers. For example, an autistic person may not like changes in their routine. If they experience sudden change they may have a meltdown or shutdown. The information sheet would explain to others how best to react e.g. 'do' be understanding about why they are upset, 'don't' expect them to be okay about sudden changes in routine, try to let them know in advance if plans need to change (strategy).

Meltdowns and Shutdowns are common coping strategies used by people with autism experiencing high levels of stress or 'overload'. An autistic person offers a helpful analogy of 'overload', if a boat overloads it sinks, if a bridge overloads it collapses. If an autistic person overloads they may have a meltdown and lose control of their behaviour (e.g. scream, shout, swear), or they may have a shutdown and withdraw from the world until they feel able to face it again.

Many people with autism when given a diagnosis are not offered additional support, and are either unaware that there is support out there or cannot access that support. It would help if practices collated a 'directory of services' to provide a list of organisations in their area that could offer help, support and advice. People with autism would like their practices to be better connected and more aware of support groups, autism friendly psychologists, counsellors and therapists, and universities conducting relevant research in their area, as these can all offer much needed support.

Useful tips for GPs

- Note autism diagnoses in your patient's computerised notes along with a brief summary of their mental health history. This will help you plan autism friendly consultations and avoid patients with autism retelling their history each time they visit.
- People with autism have told us they may feel guilty about going to their GP. Tell them that it was okay for them to come and see you, and that it is okay for them to come back and see you again if they need to.

- Sometimes it is easier for people with autism to write things down rather than say them.
- If a person with autism is in crisis it would help if their GP asked them what they found helpful in this situation in the past (if they have experienced their situation before), and if they have any coping strategies that they could use to help them now. These questions are not obvious because autistic people in crisis can often lose touch of their coping strategies. By asking these questions you will be helping your autistic patients identify what they know might help.

References

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6. Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry*, 1(2), 142-147.
7. Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208(3), 232- 238.





Further information

Please visit our website (<http://mhautism.coventry.ac.uk>) if you would like to know more about our research project and keep up to date with our news and events. You can also email us to ask any questions or to give us your feedback on this guide: mhautism.hls@coventry.ac.uk

You may also find these organisations useful:

National Autistic Society supports people with autism and their families.

W: www.autism.org

T: 0808 800 4104

E: nas@nas.org.uk

Mind supports people experiencing mental health difficulties.

W: mind.org.uk

T: 0300 123 3393 or text 86463

E: info@mind.org.uk

Samaritans work with organisations supporting those experiencing difficulty or feeling suicidal.

W: www.samaritans.org

T: 116 123 (freephone)

E: jo@samaritans.org

The **Westminster Autism Commission** recently published a report about the difficulties autistic people face when accessing healthcare. You can download it from our website

<http://mhautism.coventry.ac.uk/publications/>

The leading autism research charity **Autistica** have published a Mortality Report, summarising current knowledge into the leading causes of premature death in people with autism, and what can be done to prevent this.

You can find a copy of this report here: www.autistica.org.uk

