

Links to guidance and support

Derriford Hospital Autism Service:

Monday—Friday
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@DerrifordAutism



NAS: <https://www.autism.org.uk/>

Government Advice: NICE guidance Autism:

<https://www.nice.org.uk/guidance/qs51>

STOMP

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

The Derriford Autism Service are offering training, to get booked in please contact us.

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A brief guide to supporting Autistic Patients



Autism is a lifelong neuro-developmental Condition. In other words, the brain is wired differently. It affects social communication; social interaction; the way the world is perceived and also may have an impact on health. In many cases it is a hidden disability, some people may have a learning disability. However, up to 56% of autistic people do not have a learning disability. Autistic behaviour can be perceived sometimes as aggressive, rude and/or insensitive.

Day to day living is challenging and autistic people go through the day with high levels of anxiety. Imagine how someone with autism must be feeling when going to a GP surgery or hospital which can be a stressful event for anyone.

Autistic people are entitled by law to **Reasonable Adjustments** which must be given due consideration. To help them achieve the best healthcare outcomes, please ask if they have specific requests and offer them a Reasonable Adjustment form and Autism Hospital Passport.

It is recommended that you read Autism NICE Guidelines in order to identify the correct interventions and approach to supporting patients.

Further sources of information can be found on the back of the leaflet.



Treating and caring for someone with Autism

Many autistic people will have their parent or carer with them. Do not underestimate how important it is to have someone who knows them well and they can trust to advocate for them. This support can help keep them calm; an advocate will know what they can tolerate and can recognise the signs of distress before you do. They will also know what they will understand and this will aid communication.

Do not be surprised if the individual uses medical jargon and asks very detailed questions about their diagnosis/condition or looks it up on their phone or tablet.

Anxiety can be alleviated by knowing exactly what is going to happen. Autistic people can feel overwhelmed by anxiety and this may lead to a meltdown (loss of emotional control) which could be in the form of withdrawal or even extreme distress/aggression.

Idiosyncratic Behaviour: the autistic person may stim. Stimming is a way of self-regulation and helps them keep calm. This might include rocking, flapping, humming or vocal tics. This is helpful to the patient. Don't ask them to stop doing this.

Lack of Eye Contact is common and does not mean they are not paying attention; they are probably trying to reduce one sense to engage another and process what is happening in order to answer your questions.

Rapid Emotional Changes are caused by the different way the brain is wired in autistic people.

Clear Exchange of Information: The autistic person is likely to only answer questions asked and may not volunteer relevant information. Expand your questioning and keep checking their understanding.

Change: Autistic people struggle with change. Consistency of staff involved in care will improve care outcomes and patient experience.

Visual Aids: an illustrated leaflet will help explain the diagnosis and describe the condition along with information and ongoing care.

Pain Management: Autistic people react differently to pain. It may not be obvious through expression or body language how much pain is affecting the patient. Good communication is essential to establish how much pain someone is experiencing and what will alleviate it.

Co-morbidities: common conditions associated with autism are: ADD; ADHD; IBS; Fibromyalgia; Chronic Fatigue Syndrome; Hypermobility Syndrome; Ehlers Danlos Syndrome; poor muscle strength; Dyspraxia; Anorexia; Irlen Syndrome; Bipolar Disorder;



Oliver McGowan was a young man with a diagnosis of a Learning Disability and Autism. Sadly, he died in a Bristol hospital in 2016 aged 18 due to a rare reaction to anti-psychotic medication.

He didn't have a diagnosis of mental illness but had been given the medication to control his agitation in hospital. Paula McGowan said "We believe that if staff had been trained in understanding autism and learning disabilities, impacted by seizure activity they would have managed the situation differently."



The death of Oliver was avoidable and this is why NHS and social care staff will be provided with mandatory Learning Disability and Autism training in the future.

For more information about Oliver's Campaign please visit <https://www.olivermcgowan.org>.

Top tips for supporting an Autistic patient

- **Firstly read through information provided by the patient** including the Reasonable Adjustment form and Autism Hospital Passport.
- **Keep your language clear**, literal and brief. Allow them time to process information.
- **Never touch** an autistic person without first informing them. Tell them what you are about to do and explain what you are doing whilst you do it.
- **Use visual tools** such as a body map so the person can picture what you are telling them.
- **Ask about everything you need to know.** Someone with autism may not volunteer information.
- **Check understanding** by asking them to repeat back the information you have given to them in their own words. E.g. you have a broken arm, what are we going to do about it?
- **Understand** that if they interrupt you it's important to listen as they may forget what they wanted to say.
- **Communicate frequently** as autistic people don't like to draw attention to themselves or to make demands of others. Ask if they have everything they need for a speedy recovery e.g. water or medication.
- **Be honest.** Don't say 'This will hurt for a second' if it's likely to be 10 seconds.
- **Give clear instructions** – e.g. 'Please stand up' rather than 'Can you stand up for me?'
- **To ensure a full picture is obtained**, if the patient is supported by someone, allow them to contribute information with consent from the patient.
- **Be aware of Sensory overload:** lights, noise, smells. Machines like MRI scanners may cause sensory overload. Listening to music or noise cancelling headphones may help.
- **Anxiety** levels are higher in autistic people due to an inability to predict what is going to happen next and also a difficulty managing change.
- **Talking off subject** may indicate they are distressed and trying to distract from what is happening. It may help if you engage in a short conversation about a favourite topic.

Outpatients

Reception: If a patient tells you they have autism ask if they have a Reasonable Adjustment form and if not, offer them one. Ask if they have any immediate requests that may help to reduce their levels of anxiety.

Consider if there is a quiet area where they can wait where sensory stimulation is at a minimum. This might have less noise, low lighting and avoid bright patterns or pictures. Inform Clinic Lead if patient is waiting elsewhere.

Clear Signage or written instructions and offer help to patient with locating areas.

Photographs of staff on duty and their role will help with interacting with strangers.

Appointment Times: If appointments are likely to be delayed keep patients informed.

Consultation: When calling for patients, there may be a reason why the patient doesn't respond. For example, the patient may be wearing noise cancelling earphones and miss hearing their name being called. They may choose to wait elsewhere if they are finding the environment challenging. Don't assume because they do not immediately answer they have left; identify them; say their name to their face and introduce yourself and your role. Allow time for processing.