

## Best practice tips: supporting autistic people in a hospital setting

Autism is a lifelong disability which affects how people communicate and interact with the world. Autism is a spectrum, meaning that every autistic person has their own individual strengths and challenges. There are more than 700,000 autistic people in the UK.

Autistic people can find going to hospital very challenging. They may become overwhelmed by the loud, busy, noisy and bright environment or have difficulties understanding information or communicating their needs.

In 2019, the National Autistic Society carried out an inquiry into the experiences of autistic people in accessing public services, including mainstream health services. Over 11,000 autistic people and their families were consulted.

We found that only 22% of autistic people felt that their GP had a good understanding of autism, and only 11% felt this was true of hospital doctors. Understanding of nurses, health visitors and reception staff was rated even lower.

The following information has been put together by the National Autistic Society in collaboration with the [Autism Inclusion Award](#) accredited hospitals at Spire Healthcare. This information aims to help you:

- reduce anxiety for autistic people going to hospital
- improve autistic people's experiences of accessing hospitals
- ensure better outcomes for autistic patients.

We would like to thank the Spire Healthcare hospitals involved for their contributions to this guide, which features a variety of best practice tips and examples you can use in outpatient and inpatient care.

Every autistic person is different. It's important to offer choice where possible and not to make reasonable adjustments without discussing them with the patient first.

## **Autism health passports**

A health passport provides essential information about an autistic patient's needs in a healthcare setting, including sensory sensitivities, preferred communication methods and details of any reasonable adjustments required. This passport can be added to an autistic patient's records to help streamline their quality of care.

Ensure these are completed prior to any appointments, whether before coming into the hospital or set as a priority to complete with a patient if they arrive without one. If someone does not have a health passport, they may still require reasonable adjustments when they arrive, which should also be discussed upfront.

By using this passport and revising it when necessary, you can understand what each autistic person needs to ensure their visit is as successful as possible and amend their support as required.

You can download and fill out an autism health passport here:

[autism.org.uk/my-health-passport](https://autism.org.uk/my-health-passport)

## **Outpatients**

### Booking appointments:

When booking an appointment with an autistic patient, ask if they have a health passport they can share with you. If they do not, you can share a blank template and ask them to complete it before the appointment.

Adjustments to consider before an appointment:

- ensure their health passport is provided in the best format for the patient (picture/easy read/written)
- if a patient makes you aware that they are autistic on arrival, ask if they have a reasonable adjustment form or health passport. If not, offer them one to complete
- ask if they have any immediate requests that may help them or alleviate any anxieties. You can also suggest some options if people do not know what is available or what might help them throughout their appointment
- provide information about the appointment in advance of the appointment date, including what it will involve and what to expect - this can be done in written or picture format.

#### Sensory tips:

Provide designated quiet waiting areas or have a designated quiet room. These spaces should be low-arousal, with less noise, low lighting/mood lighting and reduced visual clutter.

Ensure sensory equipment is available. For example, create a sensory box with self-regulating items, such as ear defenders, fidget toys, stress balls or mindfulness puzzles - consider creating one for children and one for adults.

#### Communication tips:

When calling for patients to come into the appointment, don't assume they have left if they don't respond - they could be wearing noise-cancelling earphones or have chosen to wait elsewhere. Allow time for people to process what you're saying.

#### Other areas to consider in outpatient care:

Display photographs of key staff on duty and their roles to help reduce anxiety and build familiarity around new people.

If appointments are likely to be delayed, keep patients informed.

## In patients

### Pre-admissions:

Review the patient's health passport and see where you can make reasonable adjustments. If the patient does not have a health passport, identify any requirements for reasonable adjustments as early as possible.

### Adjustments to consider before admission:

- use [social stories](#) when necessary to explain what will happen during the hospital stay at a pre-admission appointment
- arrange a tour of the ward before admission or provide access to a video walk-through of the hospital
- provide a suggested packing list for planned hospital admissions in visual or written format.

### Sensory tips:

Create a sensory guide for autistic patients, including examples of what people might hear, see, touch or smell. For example, what machines beep or make noise, explaining the different uniforms of hospital staff, the location of busy common areas where lots of people might be talking or if the hand soap is scented.

Share these details in visual or written formats ahead of their appointment to help autistic people familiarise themselves and manage their expectations ahead of their visit.

### Communication tips:

Support alternative ways to communicate. These could be written formats or Augmentative or Alternative Communication (AAC) methods, such as communication books or electronic devices.

Provide written information in easy read or plain English format.

Use clear and structured language. For example, use pictorial references alongside spoken information and adjust the amount of information according to each patient's understanding.

Allow time to process information by providing longer appointment times.

#### Other areas to consider for the pre-admission preparation:

During the pre-admission appointment, try to reduce unnecessary sensory distractions during consultations and provide sensory equipment (eg noise-cancelling headphones/ear defenders, fidget toys or squishy mats) to enable self-regulation while undertaking pre-admission discussions and activities.

Be aware that autistic patients may bring a carer or family member to support them with their appointments or admission. However, try addressing the autistic person directly as much as possible rather than defaulting to whoever is with them.

## **On the wards**

Ensure that you use the information you have gained from their health passport to address any requirements for reasonable adjustments.

#### Sensory considerations:

Offer the option to use their own bedding to help support sensory differences.

If the patient needs to wear a hospital gown, check that the fabric or fit does not cause discomfort first.

Ensure the patient has access to quiet spaces.

Let the patient know they can bring personalised sensory equipment or ensure it is available (eg noise-cancelling headphones/ear defenders, fidget toys or squishy mats).

#### Communication tips:

Use appropriate communication methods, such as pictorial communication cards, easy read or standard written documents.

Use clear and structured language. Allow time to process information.

Consider using an appropriate Pain Management Scale that works best for the autistic individual.

Explain or provide a visual timetable for their hospital stay. If possible, establish a routine with set meal times or use a 'now/next' board to explain what is happening now and what will happen next in their treatment or daily schedule.

Ensure the patient knows when the doctor will come and speak to them in advance.

Schedule nurse visits for specific times, but only if this schedule can be kept reliably, which may not be possible.

#### Other areas to consider on the wards:

If required, a family member or carer could stay in the hospital overnight.

Work together with other departments to ensure that the needs of the autistic person are understood and met throughout their hospital stay. For example, if the patient requires a blood test, can you ask the relevant colleague to offer a topical anaesthetic if the patient experiences sensory hyper-sensitivity? Ensuring all the relevant staff are also aware of any necessary reasonable adjustments helps to provide a consistent approach to the patient's support needs and overall care.

Take into account that an autistic patient may have trouble sleeping away from home, which may impact their mood and intensify their sensory sensitivities.

## Hospital examinations, investigations and treatment

Continue to use the information you have gained from their health passport to address any reasonable adjustments that are required and consider the patient's needs during any examinations, investigations and treatments.

### Communication tips:

Where appropriate, use pictorial communication cards to visually communicate body parts, procedures or pain.

In some cases, use a 'now/next' board to help the patient understand what to expect.

Tell autistic patients what you are about to do and explain what you are doing while you do it using clear, structured language.

### Sensory tips:

Be aware of sensory overload, particularly when in a heightened state of arousal, which could be caused by pain, lights, noise, smells or other sensory factors. For example, machines like MRI scanners may cause sensory overload.

Ensure sensory equipment is available during examinations or treatments if needed.

### Other areas to consider:

Offer treatment choices where possible, such as liquid medication over tablets if preferred.

Use an appropriate Pain Management Scale that works best for the autistic individual.

Where necessary, arrange a best interest meeting.

## Discharge

Review the patient's health passport to see where you can reasonably adjust your discharge policy and assessment procedures. The patient should be fully involved with this process, especially if they require a complex discharge with a care plan designed around their needs.

### Sensory tips:

Discuss an appropriate discharge time with the patient where possible in case of busy periods or transport needs to reduce sensory stressors during their hospital discharge transition.

### Communication tips:

Give as much notice as possible, with daily reminders if needed, of when the patient is likely to be discharged.

Where appropriate, use social stories and/or pictures to explain going home and what to expect next.

Provide clear information and a follow-up appointment schedule.

Allow time to ask questions.

### Other areas to consider:

Be careful what you promise regarding timings and discharge - any changes may cause significant distress.

If a patient is required to take medication after their visit, try getting them to establish the routine of taking it a day or two before discharge.

Alternatively, provide clear written or visual instructions for them to take home.

We hope these tips encourage you to take action and implement sustainable changes in your hospital care.

Seeking out training and tips to support you, your colleagues and, most importantly, your patients is a critical part of delivering real change. Together, we can change the healthcare system for the better and end the health and care inequalities for autistic people.

### **Our charity is here to help**

If you require further training and support, the National Autistic Society deliver Tier 2 training for the Oliver McGowan Mandatory Training on Learning Disability and Autism. This training is for anyone who may need to provide care and support for autistic people or people with a learning disability.

Designed around an ethos of “nothing about us, without us”, you can learn from autistic people’s experiences to ensure decisions about their care consider and respect their diverse needs.

Find out more and enquire at: [autism.org.uk/tier2ommt](https://autism.org.uk/tier2ommt)