

Publications approval reference: 001559

Enhanced SECURE STAIRS team

COVID-19 guide – Autism Spectrum Condition (ASC)

17 June May 2020, Version 1

This guide intends to inform all staff within the children and young people secure estate (CYPSE) on how best to support young people with ASC during the COVID-19 pandemic. It is based on up to date evidence, and engagement with staff and children and young people. It aims to provide concise and easily accessible advice and guidance for frontline staff. This is not a complete review of all evidence, but an initial summary of helpful information and guidance. An effective practice briefing on ASC will be published in addition to this guide.

What is ASC?

ASC is an overarching term used to describe autism, Asperger's Syndrome, pathological demand avoidance (PDA) and pervasive developmental disorder (PDD). It is a lifelong developmental disability, which affects how a person communicates, relates to other people and makes sense of the world around them.

ASC is a 'spectrum condition' meaning that, while all people with autism share certain difficulties, their condition affects them in different ways. It also affects an individual differently at different points in their life and varies with:

- their stage of development
- changing environmental demands
- the presence of co-existing conditions, eg learning disability, depression, attention deficit hyperactivity disorder (ADHD) or anxiety.

Characteristics of ASC

People with ASC typically experience difficulties or misunderstandings in their daily lives as a result of their condition. People with ASC have many strengths, but may also be challenged by a range of communication issues, such as:

- difficulties in understanding the perspectives or feelings of others
- difficulties reading social cues and knowing when to speak or listen
- literal interpretation of what is said
- struggle to make eye contact
- prefer a rigid routine
- having over or under sensitivity to touch, taste, smell, light or colours and sounds.

Many people with autism experience high levels of anxiety, which can become overwhelming and lead to episodes of behavioural disturbance (sometimes described as a 'meltdown').

How to support young people with ASC effectively

Communication

- Try to have conversations in calm locations with minimal distractions. Speak slowly and with avoidance of unnecessary detail, giving 10-20 seconds for them to respond.
- Start conversations with the person's name to help focus them on what is being said and keep the language clear, concise and simple. Use short sentences, direct commands and avoid figures of speech, rhetoric and raising your voice, as this can cause sensory overload and invoke a 'meltdown'.
- Be aware that eye contact may be difficult for children or young people with ASC. The notion of personal space may not be understood; they may invade others' personal space or may themselves need more personal space than the average person.

Practical assistance to help reduce stress levels of young people with ASC

- Provide easy to read information leaflets and visual aids, such as flowcharts explaining processes and procedures. Make sure walls are not cluttered with too much information and, if possible, only have one wall with information and keep the adjacent walls clear.
- Where possible, allocate a room in quieter areas of the secure setting and arrange access to gym/library, for example at quieter times.
- Provide advance notice of changes if possible and try to maintain continuity of staffing in order to build up familiarity with the child or young person.

- Be aware that changes to routine, socialising, room or personal searches may cause distress. Try to manage operational processes sensitively by working with the person to find the best way to do things.

Support during the COVID-19 response

Young people with ASC often find changes in their routine very difficult to handle, and during this time there will be changes to all aspects of life within the secure estate. Specific advice for how to best care for children and young people with autism can be found below.

Please also see the following resources for more information:

- Social stories are short descriptions of particular situations, events or activities, which include specific information about what to expect in that situation and why ([COVID-19 social story](#)).
- National Autistic Society (NAS) resources to [improve public awareness and understanding of autism](#).
- NAS YouTube video explaining how [individuals with ASC may need extra time to process information](#).
- NAS YouTube video explaining [sensory overload](#).

Caring for children and young people with autism during the COVID-19 response

Increased anxiety levels

Anxiety is a problem for 85% of people with autism. Not only do they have high levels of personal anxiety, they are often very sensitive to distress in others. When around people who are expressing a lot of distress, they will often tend to pick this up, amplify it and start expressing high levels of distress themselves. This in turn can make other ASC symptoms become more prominent. They may also become overwhelmed by the intensity of their emotion and become behaviourally disturbed.

High levels of anxiety can be managed by:

- maintaining a calm and quiet manner when interacting with the person to help to reduce the level of emotional stimulation.

- validating their feelings using phrases like ‘I can see you are upset’, and ‘This is clearly distressing for you’.
- explaining that this is a temporary state of emotions and will pass, and then they can do something enjoyable.
- not asking ‘Why are you upset?’ or ‘What are you worried about?’; these sorts of questions require the individual to think back and go through the upsetting thought process again and then articulate worries in a coherent and sequential way. This risks escalating the anxiety.
- trying to draw the anxious state to its conclusion by focusing on how, after they have calmed down, they can move on to pursue pleasurable activities. Talking about the pleasurable activity can act as a thought block to the anxiety.
- recognising signs that they are calming down and promptly responding with praise, such as ‘Well done’, ‘Great job – you’re getting there’, ‘Thank you, I can see how hard you are trying’. The praise will reinforce their efforts to recover their emotional equilibrium.

In addition to experiencing a worsening of general levels of anxiety, the individual with autism may also have more specific anxiety disorders and may experience a worsening of these too, such as:

- phobias
- obsessive compulsive disorder, when they may become preoccupied with cleaning their room and how often they need to do this and which products to use or how often to wash their hands.

If these more specific anxieties become problematic it would be appropriate to seek further advice from the local mental health provision.

Heightened sensory sensitivities

Many young people with ASC are under reactive or over reactive to sensory stimuli or may have a mixed profile. At times of high anxiety, a young person with autism may experience a heightening of these sensory differences. They can become more sensitive or less sensitive to noise, light, smells or touch. Since educational and group activity has ceased, the young person may be spending more time than usual on the unit. This may be a different sensory environment than they are used to, and the change may cause difficulties.

Working out with the young person what has changed about the environment and exploring whether it is possible to modulate any aspect can be an important way to reduce sensory over or under stimuli. For example, use of headphones, background music or eyeshades

may help make the new environment more manageable. Tactile therapeutic interventions, such as sensory balls, or textured material may be soothing.

Identifying early signs of COVID-19 infection

People with autism may have low levels of awareness of personal illness or discomfort due to reduced sensory sensitivities. Consequently, they may not be aware that they are showing signs of COVID-19 and therefore may not seek treatment.

- If there are concerns that an autistic individual may be developing COVID-19, a temperature check may provide objective information.

Coping with unexpected changes/loss of routine

Many people with autism find having a regular routine to be an important way to manage their own anxiety and be productive. The COVID-19 restrictions have introduced many changes to day to day life and disrupted familiar routines. These changes may feel destabilising for a young person with ASC and cause rising anxiety and/or behavioural disturbance.

- This can be managed by spending time with the young person and helping them to develop a new routine.
- Identify which parts of their old routine were especially important to them. See if it is possible to retain some aspects of the old routine.
- Create a visual form of the new schedule. This process can provide structure within the chaos and restore a sense of control.

Processing COVID-19 news

There is a lot of emerging information about COVID-19. It is coming through very fast and changing every day. Young people with autistic spectrum disorders often struggle to process large volumes of information and can become overwhelmed or preoccupied by apparent inconsistencies within it. They can be helped by being advised:

- to focus on one piece of information at a time. Take time to process it and absorb it.
- noticing where the story came from so they can go back and check the information.
- to look at reliable sources of information, such as the NHS and government webpages on COVID-19.
- to check the news at the most twice a day and not to be constantly watching rolling news.
- to speak to you or another trusted adult if they are concerned about anything they have read.

Some young people may find it helpful to have a clearly written list of 'COVID-19 rules' detailing what they are expected to do or not to do. Many individuals with autism appear to have found the Government's initial advice to be confusing (eg 'try to avoid crowded places like restaurants', rather than being told: 'do not go to crowded places like restaurants').

Increased social withdrawal

Autistic individuals often have a low social drive and prefer to spend large amounts of time alone engaging in rewarding solitary activities. However, not every person with autism dislikes spending time with others and, for this second group, being alone in their room a lot may be a sign of distress. The individual may be trying to avoid the stressful unit environment but may not be deriving pleasure from being alone in their room. Social withdrawal can also be a sign of depression. Do not assume that an autistic individual is 'fine' if they are spending a lot of time alone in their room. Ask them about this and establish what has prompted this increased withdrawal.

Special interests

Many individuals with autism have special interests or hobbies that give them satisfaction, and which reduce anxiety. Facilitating pursuit of such interests may be very helpful in optimising the young person's functioning by inducing a sense of wellbeing and providing an effective distraction from worrying about COVID-19.

Are you ok?

There is often a disconnect between how an autistic person appears mood-wise and how they really feel. They can also struggle to communicate verbally when they are feeling distressed and may say they are 'fine' when they are not. As suicidal thoughts are known to be more common amongst individuals on the autistic spectrum, staff should be curious about the individual's mental state and be alert for subtle signs that the young person may be feeling distressed.

Signs such as the below may all be indicators that a young person is experiencing distress:

- Pacing or restlessness
- Pulling at clothing or fingers
- Use of repetitive phrases or questions
- Uncharacteristic irritability.

Stress management

Self-care is not selfish but is about maintaining wellbeing and optimising functioning. The following interventions can help create a sense of self-control and self-efficacy for the autistic individual, even amidst the challenges of the COVID-19 situation:

- Regular exercise every day.
- Creating a list of meaningful activities that can be done in room, eg crafting, reading, listening to music, learning a new skill or doing something new.
- Regular relaxation sessions, eg diaphragmatic breathing, muscle relaxation and visualisation.
- Having a list of chores that need doing each week and ticking them off as they are done.
- Staying in touch with people they find supportive.

Perspective taking

Regularly remind the young person that:

- this WILL end; not tomorrow, but within a matter of months.
- the majority of people who contract COVID-19 do well and return to their normal level of functioning.
- they have coped with difficult situations before and succeeded. They can draw on the skills developed in those situations and use them now.
- some of the scientists who are working on developing COVID-19 vaccines are on the autistic spectrum. It may well be that the creative strengths of autistic thinking will unlock a solution to COVID-19.