

Specialty guides for patient management during the COVID-19 pandemic

# Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the COVID-19 pandemic – relevant to all clinical specialities

November 2020, revised May 2021

As health professionals we all have general responsibilities in relation to COVID-19 and for these we should seek and act on national and local guidelines. We also have a specific responsibility to ensure that essential patient care continues with the minimum burden on the NHS. We must engage with management and clinical teams planning the local response in hospitals. We may also need to work outside our specific areas of training and expertise and the General Medical Council (GMC) has already indicated its support for this in the exceptional circumstances we may face.

As a clinician working in other fields you may have had limited clinical contact with people with a learning disability or autistic people. Research on the impact of COVID-19 on people with a learning disability showed there to be higher rates of death than for the general population, and at a younger age (see [Public Health England's COVID 19 deaths of people identified as having learning disabilities: summary](#)). Throughout the COVID-19 pandemic you will therefore be more likely to see patients with a learning disability or autistic people. We should seek the best local solutions to continue the proper management of our patients.

## Overview

People with a learning disability have higher rates of morbidity and mortality than the general population and die prematurely and have been significantly impacted by the

COVID-19 pandemic. At least 41% of them die from respiratory conditions. They have a higher prevalence of asthma and diabetes, and of being obese or underweight; all these factors make them more vulnerable to COVID-19. There is evidence that autistic people also have higher rates of health problems throughout childhood, adolescence, and adulthood, and that this may result in elevated risk of early mortality.

## Approach to supporting people with a learning disability and autistic people

The following key points should be addressed when assessing and treating a patient with a learning disability or autistic person who is suspected of having or is known to have COVID-19.

- **Be aware of diagnostic overshadowing:** This occurs when the symptoms of physical ill health are mistakenly either attributed to a mental health or behavioural problem or considered inherent to the person's learning disability or autism diagnosis. People with a learning disability or autism have the same illnesses as everyone else, but the way they respond to or communicate their symptoms may be different and not obvious. Their presentation with COVID-19 may be different from that for people without a learning disability or autism.
- **Pay attention to healthcare passports:** Some people with a learning disability and some autistic people may have a healthcare passport giving information about the person and their health needs, preferred method of communication and other preferences. Ask the person or their accompanying carer if they have one of these.
- **Ensure that clinical decisions around care and access to treatment are made on an individual basis:** People should not have a DNACPR (do not attempt cardiopulmonary resuscitation) recorded on their clinical record simply because they have a learning disability, are autistic or both. Every person has individual needs and preferences which must be taken account of and they should always get good standards and quality of care. It is also important not to make generalised judgements or assumptions about people's vulnerability or frailty based on their dependence on others for support in daily living.

- **Listen to parents and carers:** The family or carer will have a wealth of information about the individual and how they have been, including any other comorbidities and the medication the person is taking. Listen to them as well as the person you are caring for. They know the person who is unwell best and how to look after them when they are not in hospital. They also know how the person's current behaviour may differ from usual, as an indication that they are unwell. The family or carer may have short videos of the person to give you an idea of their usual self. Remember the carer they come in with may not be their usual carer at this unusual time.
- **Make reasonable adjustments:** This is a legal requirement and is important to help you make the right diagnostic and treatment decisions for an individual. You can ask the person and their carer or family member what reasonable adjustments should be made. Adjustments aim to remove barriers, do things in a different way, or to provide something additional **to enable a person to receive the assessment and treatment they need**. Possible examples include; allocating a clinician by gender, taking blood samples by thumb prick rather than needle, providing a quiet space to see the patient away from excess noise and activity.
- **Communication:** Communicate with and try to understand the person you are caring for. Check with the person themselves, their family member or carer or their hospital or communication passport for the best way to achieve this. Use simple, clear language, avoiding medical terms and 'jargon' wherever possible. Some people may be non-verbal and unable to tell you how they feel. Pictures may be a useful way of communicating with some people, but not all.
- **Understanding behavioural responses to illness, pain and discomfort:** A person with a learning disability and some autistic people may not be able to articulate their response to pain in the expected way: for example, they may say that they have a pain in their stomach when the pain is not there; may say the pain is less acute than you would anticipate; or not say they are in pain when they are. Some may feel pain in a different way or respond to it differently: for example, by displaying challenging behaviour; laughing or crying; trying to hurt themselves; or equally may become withdrawn or quiet. People who use a wheelchair may have chronic pain. Understanding what is 'normal' for that person by talking to

them, their family and carers, is crucial to helping with assessment and diagnosis. You can use pictures to help establish whether a person is in pain and where that pain is.

- **Mental Capacity Act:** People with a learning disability and autistic people do not automatically lack capacity. Assess capacity in line with the person's communication abilities and needs, and remember the principle of the Mental Capacity Act in making appropriate efforts and adjustment to enable decision making wherever possible.
- **Ask for specialist support and advice if necessary:** Your hospital learning disability team or liaison nurse can help you with issues of communication, reasonable adjustments, and assessment of pain. You may also want to make contact with your local community learning disability team if your trust does not have a learning disability liaison nurse.
- **Mental wellbeing and emotional distress:** It is estimated that 40% of adults and 36% of children and young people with a learning disability and or with autism experience mental health problems. Change in routine can have a big effect on their emotional and mental wellbeing. A change in carers because a person's usual carers are self-isolating may also have an impact. In a hospital setting, masks and protective clothing may frighten someone, make them more anxious or lead to adverse behaviours, such as hurting other people, hurting themselves or damaging property. Do not assume that this is an indication of mental illness and do your best to work with the person who is unwell, their carer or family member to find out how best to keep them calm and relaxed.

## Useful links

The [NHS My pain profile](#) helps you identify the signs that someone is in pain.

The [Disability Distress Assessment Tool \(DisDAT\)](#) is based on the idea that each person has their own 'vocabulary' of distress signs and behaviours.

[Non-Communicating Adults Pain Checklist \(NCAPC\)](#) is an 18-item checklist that helps you assess chronic pain in non-communicating adults.

[Wong and Baker's FACES Pain Rating Scale](#) uses pictures of faces to help people communicate pain intensity from 'no hurt' to 'hurts worst'.

Information on the Mental Capacity Act:

- [NHS guide to the Mental Capacity Act](#)
- [Mencap guide to the Mental Capacity Act](#)

[The Conversation article on how coronavirus could affect the wellbeing of people with intellectual disabilities](#)

[NHS information on do not attempt cardiopulmonary resuscitation decisions](#)

Information on deaths of people with a learning disability from COVID-19:

- [NHS England's report Action from learning: deaths of people with a learning disability from COVID-19](#)
- [University of Bristol report on deaths of people with learning disabilities from COVID-19](#)

## Update information

**May 2021:** the guide was updated to reflect current practice and service delivery.

**November 2020:** hyperlinks in this document were updated when the suite of guidance was moved from NHS England to NICE.

**24 March:** version 1 published.