

Speciality guides for patient management during the coronavirus pandemic

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

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“...and there are no more surgeons, urologists, orthopaedists, we are only doctors who suddenly become part of a single team to face this tsunami that has overwhelmed us...”

Dr Daniele Macchine, Bergamo, Italy. 9 March 2020

As health professionals we all have general responsibilities in relation to coronavirus 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: [www.gmc-uk.org/news/news-archive/how-we-will-continue-to-regulate-in-light-of-novel-coronavirus](http://www.gmc-uk.org/news/news-archive/how-we-will-continue-to-regulate-in-light-of-novel-coronavirus)

As a clinician working in other fields you may have had limited clinical contact with people with a learning disability or people with autism, however in 2018/19 at least 41% of people with a learning disability who died, died as a result of a respiratory condition. There is therefore, strong reason to suspect that people with a learning disability may be significantly impacted by the coronavirus pandemic. Throughout the coronavirus pandemic you will therefore be more likely to see patients with a

learning disability or people with Autism. We should seek the best local solutions to continue the proper management of our patients while protecting resources for the response to coronavirus. In addition, we need to consider the possibility that the facility for patients may be compromised due to a combination of factors, including staff sickness and supply chain shortages.

## Overview

People with a learning disability have higher rates of morbidity and mortality than the general population and die prematurely. At least 41% of them die from respiratory conditions. They have a higher prevalence of asthma and diabetes, and of being obese or underweight in people; all these factors make them more vulnerable to coronavirus. There is evidence that people with autism 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 people with autism

The following key points should be addressed when assessing and treating a patient with a learning disability or with autism who is suspected of having or is known to have coronavirus.

- **Be aware of diagnostic overshadowing:** This occurs when the symptoms of physical ill health are mistakenly either attributed to a mental health/behavioural problem or considered inherent to the person's learning disability or autism diagnosis. People with a learning disability 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 coronavirus may be different from that for people without a learning disability.
- **Pay attention to healthcare passports:** Some people with a learning disability and some people with autism may have a healthcare passport giving information about the person and their health needs, preferred method of communication and other preferences. Ask the person and/or their accompanying carer if they have one of these.
- **Listen to parents/carers:** The family or carer will have a wealth of information about the individual and how they have been, including any other co-morbidities 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. But 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/family member what reasonable adjustments should be made. Adjustments aim to remove barriers, to do things in a different way, as well as to provide something additional to enable a person to receive the assessment and treatment they need. 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/carer or their hospital/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/discomfort:** A person with a learning disability and some people with autism may not be able to articulate their response to pain in the expected way: eg 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: eg by displaying challenging behaviour; laughing or crying; trying to hurt themselves; or equally may become withdrawn or quiet. People who are wheelchair dependant 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 people with autism 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/liaison nurse can help you with issues of communication, reasonable adjustments, 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 them, make them more anxious and lead to adverse behaviours, such as hurting other people, hurting themselves and destroying 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

*My pain profile* helps you identify the signs that someone is in pain:

<https://www.dyingmatters.org/sites/default/files/user/images/pain%20assessment%20tool%20Notts%20final%20doc.pdf>

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

[https://www.wamhinpc.org.uk/sites/default/files/Dis%20DAT\\_Tool.pdf](https://www.wamhinpc.org.uk/sites/default/files/Dis%20DAT_Tool.pdf)

Non-Communicating Adults Pain Checklist (NCAPC) is an 18-item checklist that helps you assess chronic pain in non-communicating adults. [https://cpb-us-](https://cpb-us-e1.wpmucdn.com/wordpressua.uark.edu/dist/9/300/files/2017/04/Non-Communicating-Adult-Pain-Checklist.pdf)

[e1.wpmucdn.com/wordpressua.uark.edu/dist/9/300/files/2017/04/Non-Communicating-Adult-Pain-Checklist.pdf](https://cpb-us-e1.wpmucdn.com/wordpressua.uark.edu/dist/9/300/files/2017/04/Non-Communicating-Adult-Pain-Checklist.pdf)

Wong and Baker's FACES Pain Rating Scale uses pictures of faces to help people communicate pain intensity from 'no hurt' to 'hurts worst':

<https://wongbakerfaces.org/instructions-use/>

Information on the Mental Capacity Act:

- <https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/>
- <https://www.mencap.org.uk/advice-and-support/mental-capacity-act>

Mental wellbeing: <https://theconversation.com/how-coronavirus-could-affect-the-wellbeing-of-people-with-intellectual-disabilities-133540>