

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

This guidance aims to enable clinical staff to give people with learning disabilities equitable access to care and treatment for COVID-19. In every situation, they have the right to be treated with the same dignity and respect as any other citizen.

As a clinician working in other fields you may have had limited clinical contact with people with learning disabilities or autistic people. In Scotland around one-third of deaths of people with learning disabilities were as a result of a respiratory condition. There is therefore, strong reason to suspect that people with learning disabilities may be significantly impacted by the coronavirus pandemic. Throughout the coronavirus pandemic you will be more likely to see patients with learning disabilities or autistic people.

Overview

People with learning disabilities and with autism are at higher risk of serious illness from Coronavirus (COVID-19). The Clinical Frailty Scale (CFS) **should not** be used to direct clinical decision making in people with learning disabilities or autism (in line with the [updated NICE rapid COVID-19 critical care guidelines](#)). Learning disabilities or autism should **never** be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death. Learning disabilities and autism are not fatal conditions. People with learning disabilities have higher rates of morbidity and mortality than the general population and die prematurely. Respiratory conditions are a major cause of death.

Swallowing problems, constipation, reflux, posture, and oral health problems are more common in people with learning disabilities and can be related to respiratory safety. People with learning disabilities also have a higher prevalence of asthma and diabetes, and of being obese or underweight; 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 autistic people

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 and communication passports:** Some people with a learning disability and some people with autism will 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. An example of this is [PAMIS's digital passports](#).
- **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. Visual and hearing impairments are more common in people with learning disabilities and should always be considered. People with a learning disability use a variety of different communication methods, however they still have rights, will and preferences and every effort must be made to establish what these are.

- **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 individuals 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. The Scottish Patient Safety Programme has produced [guidance on improving outcomes for children at greater risk of severe sepsis, including those with profound and multiple learning disabilities](#), and recommends that clinicians apply a reduced threshold and consider treatment with fewer signs.
- **Adults with Incapacity (Scotland) Act 2000:** people with learning disabilities and autism should be supported to be involved in decisions about their own health and care, and it should not be automatically assumed that they lack capacity. Assess capacity in line with the person's communication abilities, preferences and needs. The principles of the Adults with Incapacity Act **require** that decisions must benefit the person, be the least restrictive option, take account of the wishes of the person, take account of the views of carers and encourage the person to make their own decisions. <https://www.mwscot.org.uk/law-and-rights/adults-incapacity-act>
- **Ask for specialist support and advice if necessary:** Your hospital learning disability team/liason nurse can help you with issues of communication, reasonable adjustments, assessment of pain. You may also want to contact your local community learning disability team if your service 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. 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.

- **Profound and Multiple Disabilities:** People who have a profound learning disability and some people with autism will require 24 hour supervision and support by family or known carers. This may mean that staff will need to consider carers becoming part of the team to support the person. This additional support could also monitor the impact and interventions required by comorbidities such as epilepsy.
- **Postural Care:** It is important to ensure appropriate positioning/24 hour postural care is considered especially for those with complex disabilities. The guidance and resources are on the [NHS NES website](#) and the evidence for the [importance of postural care](#) is well documented.

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

Non-Communicating Adults Pain Checklist (NCAPC) is an 18-item checklist that helps you assess chronic pain in non-communicating adults. <https://cpb-use1.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/>