



## Factsheet 34

Updated on 26 February 2021

# Supporting people with a Learning Disability and their families and carers, during the COVID-19 pandemic

*This factsheet has been designed for use by healthcare professionals only.*

We know that the pandemic has been a time of increased anxiety for people and for those with a Learning Disability (LD), particularly those who have existing respiratory conditions, it can be particularly stressful. The recent decision to offer all adults on the GP Learning Disability Register the vaccine as part of priority group 6<sup>1</sup> is welcome news for many families, but healthcare professionals must continue to identify and support those not currently eligible.

Data from January – November 2020 indicates that the risk of death involving COVID-19 is more than three times greater for people with LD than those without,<sup>2</sup> and that recorded deaths from the virus were more widespread across adult age groups in people with LD than in the general population.<sup>3</sup> For relatives and carers, awareness of such statistics is likely to cause further anxiety, particularly for those currently unable to visit and support loved ones in residential care.

It is important therefore to be sensitive to the needs of people with LD and their carers when they access healthcare services, whether due to COVID or for routine appointments. The following guidance should be followed:<sup>4</sup>

- There may be a need for detailed planning where people are used to specific routines and are unsettled by change.
- Make sure the person, and/or their relative or carer, is included in discussions and decisions, so they will have the best chance of understanding what is happening.
- Explain why you have to wear PPE, particularly if someone is having trouble recognising you. If you have to wear a mask, consider attaching a laminated photo of yourself to your clothes.
- Similarly, explain changes to processes and procedures – e.g. if things are being done in a less 'hands on' way.
- Find out if the person you are supporting has a hospital passport and familiarise yourself with their details and preferences.
- Provide an opportunity for the person and/or their carer to ask questions and answer them as clearly and honestly as you can.



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### Clinical management of COVID patients with LD

We know that there is a higher prevalence of asthma and diabetes among people with LD, and data shows that in 2018/19 at least 41% of people with a learning disability who died, died as a result of a respiratory condition.<sup>5</sup> This group is therefore likely to be more vulnerable to COVID-19 and clinicians are likely to see more people with LD than in their everyday practice, and the following points should be addressed during consultation and/or treatment:

- Be aware of **diagnostic overshadowing**. The presentation of coronavirus may be different in people with LD than in those without, and their response to, or communication of, their symptoms may also differ to other patients. It is vital that symptoms and behaviours are fully investigated and not automatically attributed to their LD diagnosis.
- Listen to those who know the person well. Carers, whether unpaid or paid (if they are the person's regular carer), will be able to tell you a great deal about the person's usual behaviours, as well as their medications, co-morbidities, and routines. However, it is also important to ensure the person with LD has their voice heard.
- Make reasonable adjustments. This is a legal requirement and resources are available to support you.<sup>6</sup> Examples of reasonable adjustments include allocating a clinician by gender, taking blood samples by thumb prick rather than a needle, or providing a quiet space to see the patient away from excess noise and activity.
- Understand responses to pain and discomfort. People with LD may not be able to articulate the specific location of their pain or may suffer from chronic pain that can be confused with new symptoms. Again, talking to the person and their carers is key, and using resources such as pictures or models may help to identify particular symptoms.
- Ask for specialist support if necessary. Your local hospital and/or local authority will be able to direct you to dedicated LD teams.

The NHS have provided further evidence-based guidance for clinicians about how best to support people with LD who have coronavirus<sup>7</sup>.

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**Supporting people with a Learning Disability and their families and carers, during the COVID-19 pandemic****Impact on relatives and family carers**

Care Act easements mean that people with LD may have experienced a reduction in statutory care and support services, while relatives may also have chosen to temporarily cohabit with a loved one who has LD to avoid losing contact due to lockdown restrictions.<sup>8</sup> Both of these scenarios can result in family members taking on increased caring responsibilities and they may require support to manage their own health and wellbeing.

If carers, or those they care for, develop symptoms of coronavirus they should follow the national guidance around self-isolation.<sup>9</sup> However, if neither party is symptomatic, they can access respite care (under an exemption to lockdown restrictions) and may be able to form a support bubble. You may also wish to direct them to information about further sources of support that are available nationally or locally.<sup>10</sup>

**References:**

<sup>1</sup> GOV UK (2021): <https://www.gov.uk/government/news/jcvi-advises-inviting-people-on-learning-disability-register-for-vaccine>

<sup>2</sup> Office for National Statistics (2021): <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020>

<sup>3</sup> GOV UK (2020): <https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities/covid-19-deaths-of-people-identified-as-having-learning-disabilities-summary>

<sup>4</sup> SCIE (2020): <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff>

<sup>5</sup> NICE (2020): <https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/learning-disability-autism-during-pandemic.pdf>

<sup>6</sup> GOV UK (2018): <https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability>

<sup>7</sup> NHS (2021): <https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/action-from-learning/people-with-a-learning-disability-and-coronavirus/>

<sup>8</sup> GOV UK (2020): <https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities>

<sup>9</sup> NHS (2021): <https://www.nhs.uk/conditions/coronavirus-covid-19/self-isolation-and-treatment/when-to-self-isolate-and-what-to-do/>

<sup>10</sup> GOV UK (2021): <https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care/guidance-for-those-who-provide-unpaid-care-to-friends-or-family>