

Long-COVID in Individuals With an Intellectual Disability

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The purpose of this document is to:

- Provide families with background information on newly recognized cognitive impairments, or trouble remembering, learning new things, concentrating, or making decisions, among adults with an intellectual disability, resulting from the effects of Long-COVID
- Suggest what actions might be taken to identify such impairments
- Provide remedial supports

What is Long-COVID?

Long-COVID is defined by the Centers for Disease Control and Prevention (CDC) as being infected with the COVID-19 virus and then experiencing long-term physical and mental effects from the infection.¹ These long-term effects can be a wide range of new, returning, or ongoing health problems that affect daily functioning and last more than three months after the initial COVID-19 infection.

What is the possible impact of Long-COVID?

Some individuals who have had COVID-19 may experience Long-COVID. While little data exist about the symptoms of Long-COVID specific to adults with an intellectual disability² (including Down syndrome³), data are beginning to emerge in the general population.⁴ The data show some adults may remain at an increased risk for dementia, epilepsy, and 'brain fog' for up to two years after contracting COVID-19. 'Brain fog' includes problems with thinking, motivation, and carrying out life activities and tends to be the most common complaint among adults with Long-COVID. Persistent symptoms of 'brain fog' should be taken seriously and reported to a medical professional, such as a primary care physician.⁵

Key Points

- Long-COVID can include 'brain fog' (problems with thinking, motivation, and carrying out life activities).
- Adults with intellectual disability infected with the COVID-19 virus may experience Long-COVID.
- Partners, families, and agencies should look for changes in cognitive functions that may be due to Long-COVID.
- Screening and assessments should be undertaken to determine the presence of Long-COVID.
- Accommodations and adaptations should be implemented to help mitigate effects of Long-COVID.

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What are the most common symptoms of 'brain fog' related to Long-COVID?

- Confusion
- Delays in responding when spoken to
- Difficulty paying attention
- Trouble maintaining focus
- Difficulty following conversations
- Difficulty multitasking
- Difficulty planning
- Difficulty understanding or remembering instructions
- Feeling "out of it"
- Being forgetful
- Impulsiveness
- Lack of mental clarity
- Language use problems
- Losses in train of thought
- Memory impairment
- Poor judgment

Data from researchers indicate some COVID-19 symptoms have a more harmful effect on post-COVID-19 functioning. For example, loss of taste and smell during the infectious phase has been linked to more severe cognitive impairments months after infection, even if other symptoms have been mild.⁶

Keep in mind that these symptoms must be new and not present before being infected with COVID-19.

Key Supports for Adults with Long-COVID

- Ensure appropriate periodic medical and health checks for physical symptoms
- Track function and cognitive abilities and document changes
- Adapt care/support approaches as you would for mild cognitive impairment or early dementia
- Implement a 'dementia care plan' in anticipation of changing needs
- Confer with clinicians with Long-COVID experience for overall post-COVID care advice
- Refer to neurologist or other clinician when cognitive symptoms worsen

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What to do if an individual with an intellectual disability is suspected of experiencing Long-COVID?

- Caregivers should seek a doctor's assessment for adults with an intellectual disability who are showing symptoms of new impairments in thinking after having COVID-19. If a diagnosis of Long-COVID is given, physical and mental health concerns should be closely monitored by both caregivers and medical professionals and support services sought as needed.
- Families and doctors should be cautious and avoid “diagnostic overshadowing”, which occurs when the assumption is made that any change in the person's ability is due to their disability without considering other reasons.⁷ Having an accurate knowledge of the individual's abilities before having COVID-19 is extremely helpful. The National Task Group-Early Detection Screen for Dementia⁸ instrument can be used for this purpose. NTG-EDSD (the-ntg.org)
- Provider and caregiver best practices is to provide aids to lessen difficulty with everyday tasks due to confusion, forgetfulness, disorientation, gait problems, and/or other Long-COVID symptoms.⁹ This includes changes to the home or workplace that can assist with memory and cues for carrying out daily routines, such as use of a visual schedule or checklist. Rehabilitation specialists, such as occupational, physical, and speech therapists, can be helpful with suggesting adaptations to a residence and daily routines.

What can I do to help someone with an intellectual disability who may have Long-COVID?

- Share any suspicions you have with the person's support provider or primary care provider
- Request that the provider make accommodations to help the person with the additional impairments they are experiencing
- Make sure that all medical care is appropriate for conditions being experienced
- Ask the provider if any of the medications currently prescribed could be worsening the person's behavior
- Communicate interventions and supports to all the person's key providers, including residential and health

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Additional information about Americans with Disabilities Act and Long-COVID

Adults with an intellectual disability are covered under the Americans with Disabilities Act (ADA); for those with Long-COVID, they are additionally entitled to protection from discrimination associated with having Long-COVID. They are also entitled to “full and equal opportunities to participate in and enjoy all aspects of civic and commercial life” and “reasonable modifications” to accommodate their Long-COVID related limitations, such as the aids and environmental modifications mentioned above.¹⁰ If there are situations where this protection is not made available, it is suggested to contact the Disability Rights Agency in your state to seek advice.

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This document was adapted from: National Task Group. (2022, October 5).

Advisory on Long-COVID and impact on cognitive function in adults with intellectual disability. www.the-ntg.org.

1 Centers for Disease Control and Prevention. Long COVID or post-COVID conditions. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>

2 Rawlings, G. H., & Beail, N. Long-COVID in people with intellectual disabilities: A call for research of a neglected area. *British Journal of Learning Disabilities*, 29 August 2022. 1-8. <https://doi.org/10.1111/bld.12499>

3 Majithia, M., & Ribeiro, S. P. COVID-19 and Down syndrome: the spark in the fuel. *Nat Rev Immunol*. 2022 Jul;22(7):404-405. doi: 10.1038/s41577-022-00745-w.

4 Taquet, M., Sillett, R., Zhu, L., Mendel, J., Campilison, I., Dercon, Q., & Harrison, P. J. Neurological and psychiatric risk trajectories after SARS-CoV-2 infection: an analysis of 2-year retrospective cohort studies including 1 284 437 patients. *Lancet Psychiatry*, 2022; 9: 815-27. <https://www.thelancet.com/action/showPdf?pii=S2215-0366%2822%2900260-7>

5 Amen Clinics. (2019) When does brain fog become a concern? <https://www.amenclinics.com/blog/when-does-brain-fog-become-a-concern/>

6 Duong, D. Even mild COVID-19 may have long-term brain impacts. *CMAJ*, August 30, 2021, 193 (34) E1360-E1361; DOI: <https://doi.org/10.1503/cmaj.109595><https://www.cmaj.ca/content/193/34/E1360>

7 The Joint Commission. Sentinel Event Alert 65: Diagnostic overshadowing among groups experiencing health disparities. *Sentinel Event Alert*, Issue 65, June 22, 2022. <https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/sentinel-event/sea-65-diagnostic-overshadowing-6-16-22-final.pdf>

8 Esralew, L., Janicki, M. P., DiSipio, M., Jokinen, N., Keller, S. M. & Members of the National Task Group Section on Early Detection and Screening. (2013). *National Task Group Early Detection Screen for Dementia: Manual*. <https://www.the-ntg.org/screening-assessment>

9 Jokinen, N., Janicki, M. P., Keller, S. M., McCallion, P., Force, L. T. and the National Task Group on Intellectual Disabilities and Dementia Practices. (2013). Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 10(1), 1-24

10 U. S. Equal Employment Opportunity Commission (July 12, 2022). What You Should Know About COVID-19 and the ADA, the Rehabilitation Act, and Other EEO Laws. <https://www.eeoc.gov/wysk/what-you-should-know-about-covid-19-and-ada-rehabilitation-act-and-other-eeo-laws>