

# Long-haul COVID

## Post-acute Sequelae SARS-CoV-2 Infection (PASC) in People with IDD



People with intellectual and developmental disabilities (IDD) are at a greater risk of infection and poorer COVID-19 related health outcomes than the general population. Prevalence of comorbidities, living in congregate settings, and difficulties practicing preventative measures contribute to this risk; however, the inability to effectively communicate symptoms of illness may be the most significant hurdle to identifying and managing symptoms of COVID-19 infection, especially for those experiencing the lasting effects of long-haul COVID.

### ■ What is long-haul COVID?

In its acute phase, mild or moderate COVID-19 infection lasts approximately two weeks for most people. Over time, there have been increased reports of new or ongoing symptoms that can last four or more weeks or even months after testing positive for the virus. The medical term for these lingering symptoms is post-acute sequelae of COVID-19 (PASC) but may also be known as long-haul COVID, chronic COVID, or post-acute COVID-19, among others. Little is known about who gets them and why. Because long-haul COVID remains an emerging condition, research studies have been unable to answer important questions: Who is at risk for long-haul COVID? What are the symptoms? What is the best treatment?

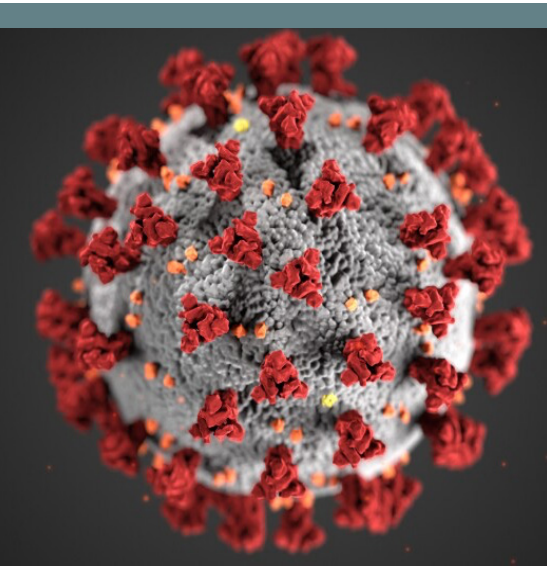
Long-haul COVID can happen to anyone who has had COVID-19, even if the illness was mild or if they were initially asymptomatic. Currently, there are no specific risk factors linked to long-haul COVID. Still, if we know people with IDD are at a higher risk for contracting COVID-19 infection, we must be aware of the potential higher risk they may also experience long-haul COVID symptoms.

### ■ What does it look like?

COVID-19 infection can attack the body in many ways, resulting in damage to the heart, lungs, kidneys, nervous system, and other organs. Mental health changes may arise from unresolved pain, fatigue, neurological changes, or fear of dying. Some people report their long-haul COVID symptoms are nothing like the initial symptoms they experienced when first infected. Identification of long-haul COVID is challenging due to the wide range of subjective symptoms, which are often reported verbally by those infected with COVID-19.

Reporting symptoms may be challenging for a person with IDD who may have trouble describing the problems they are experiencing. Those whose disabilities that affect their hearing, vision, and/or speech are more likely to face barriers to communication. It is important for supporters to understand and recognize other methods of communication in the IDD population, especially behavioral presentations of long-haul COVID symptoms.

Research studies regarding long-haul COVID are ongoing due to the uncertainty surrounding risk factors, length of illness, and unpredictable, multisystem symptoms. The list of long-haul COVID symptoms is lengthy, inconsistent, and will evolve as we learn more about this condition. According to the Centers for Disease Control and Prevention (2021), the current most common long-haul COVID symptoms are listed here, along with how they might appear in a person with communication differences.



Long-haul COVID Symptom	How It May Look in a Person with IDD
<b>Difficulty breathing or shortness of breath</b>	<ul style="list-style-type: none"> <li>• Easily fatigued with minimal exertion</li> <li>• Refusing to perform self-care tasks</li> <li>• Increased agitation and/or anxiety</li> <li>• Restlessness</li> <li>• Refusing to eat due to difficulty coordinating breathing and swallowing</li> <li>• Requiring additional time to complete meals, which may be first noted as a slower intake of thin liquids</li> </ul>
<b>Tiredness or fatigue</b>	<ul style="list-style-type: none"> <li>• Lack of interest in regular routine</li> <li>• Choosing not to participate in favorite activities</li> <li>• Falling asleep during waking hours or sleeping more than usual</li> <li>• Increased irritability or “cranky” behavior</li> <li>• Limited patience</li> <li>• Exhibiting a general lack of energy</li> <li>• Refusing to walk even short distances</li> <li>• Difficulty thinking or concentrating (“brain fog”)</li> <li>• Confused look toward familiar persons</li> <li>• Changes in the person’s ability to understand or use language</li> <li>• Becoming unable to perform activities they were previously able to perform, such as engaging in preferred activities or completing self-care tasks</li> <li>• Refusing to perform activities of daily living (ADLs)</li> <li>• Appearing unfamiliar with previously known environments or situations</li> <li>• Lack of concentration</li> <li>• Changes in sleep patterns, oversleeping, or sleeplessness</li> </ul>
<b>Cough</b>	<ul style="list-style-type: none"> <li>• Coughing, particularly around mealtimes</li> <li>• Appearing unable to handle their secretions</li> <li>• Repetitive throat clearing</li> <li>• Increased drooling</li> </ul>
<b>Chest pain</b>	<ul style="list-style-type: none"> <li>• Scratching, hitting, or rubbing at chest</li> <li>• Agitation</li> <li>• Anxiety</li> </ul>
<b>Stomach pain</b>	<ul style="list-style-type: none"> <li>• Inserting their hand deep into their mouth (hand-mouthing)</li> <li>• Food refusal</li> <li>• Physical or verbal aggression around mealtime</li> <li>• Distress in the middle of the night</li> <li>• Pica (eating inedible objects)</li> </ul>
<b>Headache</b>	<ul style="list-style-type: none"> <li>• Headbanging</li> <li>• Headbutting</li> <li>• Hitting or slapping self</li> <li>• Sticking objects in ears or nose</li> <li>• Withdrawal from areas of light or noise</li> <li>• Sitting with head in lap</li> <li>• Covering head</li> <li>• Hands over ears or face</li> </ul>

<b>Fast-beating or pounding heart (heart palpitations, tachycardia)</b>	<ul style="list-style-type: none"> <li>• Expressing feelings of doom/near death</li> <li>• Sweating</li> <li>• Dizziness, light-headedness, or fainting</li> <li>• Clutching chest or putting a hand over heart or neck</li> <li>• Rapid breathing</li> </ul>
<b>Joint or muscle pain</b>	<ul style="list-style-type: none"> <li>• Hitting area experiencing pain</li> <li>• Refusing to participate in routine activities</li> <li>• Decreased mobility or limping</li> <li>• Inability or refusal to bear weight</li> <li>• Guarding or holding the affected area close to the body</li> </ul>
<b>“Pins-and-needles” feeling (neuropathy)</b>	<ul style="list-style-type: none"> <li>• Inability to sit still</li> <li>• Pacing</li> <li>• Scratching or hitting the affected area</li> <li>• Balance and coordination difficulties</li> <li>• Increase in injuries due to numbness</li> <li>• Sensitivity to touch</li> </ul>
<b>Diarrhea</b>	<ul style="list-style-type: none"> <li>• Increase in bowel incontinence for a person who typically has few/minimal accidents</li> <li>• Abdominal guarding due to cramps</li> <li>• Maintaining a fetal position</li> </ul>
<b>Sleep problems</b>	<ul style="list-style-type: none"> <li>• Daytime drowsiness</li> <li>• Inability to stay asleep</li> <li>• Wandering at night</li> </ul>
<b>Fever</b>	<ul style="list-style-type: none"> <li>• Sleeping more than usual</li> <li>• Sweating</li> <li>• Skin is warm or hot to touch</li> <li>• Increased thirst</li> <li>• Shivering</li> <li>• Choosing not to participate in activities or ADLs</li> <li>• Decreased cognition</li> <li>• Flushed face</li> </ul>
<b>Dizziness on standing (lightheadedness)</b>	<ul style="list-style-type: none"> <li>• Increase in the number of falls</li> <li>• Swaying or wobbling</li> <li>• Appearing clumsy</li> <li>• Avoiding stairs or uneven pavement for fear of falling</li> <li>• Refusing to stand/walk</li> </ul>
<b>Rash</b>	<ul style="list-style-type: none"> <li>• Skin-picking or scratching the affected area</li> <li>• Guarding the affected area</li> <li>• Self-removal of irritating clothing</li> </ul>
<b>Mental health changes: Anxiety Depression Post-traumatic stress disorder (PTSD) Insomnia Paranoia Delusions, Hallucinations Mania</b>	<ul style="list-style-type: none"> <li>• Anxiousness</li> <li>• New or increasing self-abusive behavior</li> <li>• Withdrawing from usual activities</li> <li>• Self-isolation</li> <li>• Nighttime awakening</li> <li>• Acting fearful of supporters and/or healthcare providers</li> <li>• Appearing to respond to sounds or sights that are not there</li> <li>• Increased aggression</li> <li>• Impulsive behavior</li> </ul>

<b>Changes in smell or taste</b>	<ul style="list-style-type: none"> <li>• Decreased appetite</li> <li>• Refusing favorite foods</li> <li>• Unplanned weight loss</li> <li>• Dehydration</li> <li>• Eating foods they would not usually choose</li> <li>• Pica</li> </ul>
<b>Changes in menstrual cycle</b>	<ul style="list-style-type: none"> <li>• Irregular bleeding</li> <li>• Changes in duration</li> <li>• Amenorrhea (missing one or more menstrual periods)</li> </ul>

## How do we respond?

Supporting a person with long-haul COVID requires a multidisciplinary effort focused on observing, reporting, and developing person-specific treatment plans. Although interventions for long-haul COVID may change with further research, the roles and responsibilities of DSPs, nurses, and community healthcare providers are often consistent with the management of other medical or psychiatric issues. Listed here are interventions to be considered and the discipline bearing primary responsibility for them.

Intervention	Direct Support Professional (DSP)	Nurse	Community Healthcare Provider
Educate the person previously infected with COVID-19 about signs and symptoms of long-haul COVID and encourage self-reporting, if able	✓	✓	
Educate caregivers, including family members, on how to identify and report signs and symptoms of suspected long-haul COVID symptoms	✓	✓	✓
Observe for changes in the person's day-to-day routine and activities	✓	✓	
Document changes in the person's condition	✓	✓	✓
Monitor for trends in identified symptoms. Is the person getting better, worse, or stable?	✓	✓	
Document vital signs, pulse oximetry, intake and output, and person-specific notes	✓	✓	
Review tracking forms related to the person's medical and behavioral monitoring		✓	✓
Report when a person is "not acting right" to a healthcare provider	✓	✓	
Develop person-specific plans to manage long-haul COVID symptoms and mitigate risk		✓	✓

Intervention	Direct Support Professional (DSP)	Nurse	Community Healthcare Provider
Recommend interventions based on the person's physical and cognitive abilities		✓	✓
Implement supportive measures based on a person-specific plan	✓	✓	✓
Evaluate for new medical or psychiatric conditions, or exacerbation of an existing diagnosis		✓	✓
Refer to specialty healthcare providers for further assessment of medical, nutritional, or psychiatric concerns			✓
Assess for worsening of symptoms during scheduled and as-needed visits		✓	✓
Observe and report suspected medication side effects to the nurse and/or prescriber	✓	✓	
Routinely review medications for side effects that may mimic or mask long-haul COVID symptoms		✓	✓
Order diagnostic tests for evaluation and treatment of new symptoms and/or worsening of existing conditions			✓
Continue to research long-haul COVID symptoms, risk factors, and interventions	✓	✓	✓

### ■ When to seek immediate medical attention:

- New or increased trouble breathing
- Persistent pain or pressure in the chest or upper abdomen
- New onset of confusion
- Change in level of consciousness/alertness
- Inability to wake or stay awake
- Pale, gray, or blue-colored skin, lips, or nail beds, depending on skin tone
- Any other concerning signs or symptoms, or feelings that the person is "not themselves or not acting quite right"

***Not an all-inclusive list***

## ■ Considerations for People with IDD

- Presentation of long-haul COVID symptoms may be different in people with communicative challenges compared to that of the population at large. It is essential that supporters understand, document, and report changes in behavior, as these may be signs of COVID-related issues. In doing so, the healthcare team may more effectively advocate for the person, implement the appropriate interventions, and minimize further complications related to long-haul COVID.
- Documenting the initial onset or diagnosis date of COVID-19 infection is vital to linking changes in the person's condition to long-haul COVID symptoms. This date should be noted in the person's medical record or chart and should reflect the day of official COVID-19 diagnosis by a healthcare provider or positive test result. Ongoing documentation by the person's direct support team is also crucial to identifying patterns of symptoms and supporting a diagnosis of post-acute sequelae of COVID-19 (PASC).
- Communication of a person's COVID-19 diagnosis is essential to continued monitoring and support by the healthcare team. Consider implementing easily identifiable measures of long-haul COVID risk by applying a COVID-specific label or sticker to a physical chart or notating in a designated area of the medical record.
- Education and training for supporters should be person-specific and ongoing. This is critical due to the wide variety of symptoms associated with long-haul COVID, presentation of these symptoms in the IDD population, and ongoing research surrounding long-haul COVID indicators.
- Interventions should be based on the person's physical and cognitive abilities. Healthcare providers must be creative in developing strategies to encourage lung expansion and movement. Examples include: having a person blow up balloons or blow bubbles if they cannot effectively use an incentive spirometer, playing games with the blown-up balloon to promote physical activity, or turning on the person's favorite comedy to encourage laughter.

*Developed by IntellectAbility in collaboration with the Missouri Division of Developmental Disabilities*