

What is 'long COVID' and how to report on it

Until recently, the narrative of COVID-19 has been that it will either be life threatening, or it will feel like a bout of the flu; take some rest and you will recover quickly – especially if you're young. But there is growing anecdotal and scientific evidence that some people are not recovering so quickly. There are growing reports of people having serious physical and neurological symptoms that can last for weeks and sometimes months affecting your ability to return to work or even lead a normal life. But when these long haulers get tested for COVID-19 weeks or months into their illness, the results are negative. So why are they still feeling the effects of the virus?

On average, long-haulers who tested negative experienced the same set of symptoms as those who tested positive for COVID-19: fatigue, persistent joint pains, shortness of breath and a loss of smell for months after they have recovered from the initial illness.

But their negative result leaves them in a strange, painful limbo, instead of indicating they have been completely cured and ironically shuts them out of research and treatments. Sufferers may be unable to get support from family and friends who do not understand why they are ill for so long, and many are put under pressure to return to work.

What do you need to know?

Question 1

Is long COVID a medical term?

There is no consensus on the medical definition of 'long COVID' at the present time. The following is a suggestion from a British Medical Journal panel in early September 2020: long COVID is a condition of not recovering for several weeks or months following the start of symptoms that were suggestive of COVID19, whether the person was tested for the SARS-CoV-2 virus that causes COVID-19. Advocacy groups prefer this definition because there are some with long COVID whose insurance claims are being denied, if they had never been tested for the SARS-CoV-2 infection.

Long COVID has puzzled scientists and left those affected feeling unsupported by health systems that are only just discovering the long-term impacts of the disease. Sufferers may struggle to get the medical support or recognition for their condition.

The World Health Organization (WHO) acknowledges that it does not yet fully understand COVID-19. It says that typical recovery times are two weeks for patients with mild illness, and up to eight weeks for those with severe illness, but it recognizes that there are people who continue to have symptoms for longer.

In such cases, the WHO says, symptoms may include extreme fatigue, persistent cough or exercise intolerance (getting tired very quickly when you exercise). The virus can cause inflammation in the lungs, cardiovascular and neurological systems, and it can take a long time for the body to recover.

What is alarming is that newer data is emerging about long COVID-19 sufferers who seem to develop what could be longer-term brain problems. These include confusion, memory problems, dizziness, and thinking difficulties, among others. Experts in neuro-infectious disease have seen this before with Ebola survivors, HIV/AIDS patients, and other patients of viral illness. COVID-19 is a new disease but these early reports raise concerns about the long-term recovery of survivors and the possible impacts of the virus on the brain.

Question 2

What do scientists know so far about why people develop long COVID?

There are lots of ideas, but no definitive answers. The virus may have been cleared from most of the body but continues to linger in some small pockets. “If there’s long-term diarrhea then you find the virus in the gut, if there’s loss of smell it is in the nerves – so that could be what’s causing the problem,” says Prof Tim Spector, from King’s College London.

The coronavirus can directly infect a wide variety of cells in the body and trigger an overactive immune response which also causes damage throughout the body. One thought is the immune system does not return to normal after COVID-19 and continues to damage itself.

The infection may also alter how people’s organs function. This is most obvious with the lungs if they become scarred causing long-term breathing problems. COVID-19 is not the only coronavirus that has caused long term health issues for survivors. The SARS-CoV-2 virus, which causes COVID-19, belongs to the coronavirus family, and long-term problems have been seen after infection with Severe Acute Respiratory Syndrome (SARS) or Middle East Respiratory Syndrome (MERS), which are also types of coronavirus.

SARS appeared in 2002 in China. A 15-year follow-up study of patients found that most lung recovery took place within two years, but some mild lung damage remained indefinitely in more than a third of recovered patients. Researchers also found lung function abnormalities among MERS survivors indicating diseases that cause airways to become narrow, which results in long-term breathing problems.

Question 3

Do you need to have had severe COVID-19 to get long COVID?

Data from the Royal Australian College of General Practitioners suggests up to 80 per cent of people who require hospitalization with COVID-19 will experience post-COVID-19 symptoms. Early trends in the COVID Symptom Study suggest that long COVID was about twice as common in women as in men and that the average age of someone presenting with it was about four years older than people who had what might be labelled as 'short COVID'. The average age for someone suffering with long COVID is 45. Young people can be long haulers, too.

A study from the US found that in addition to adults and those with chronic conditions reporting long-term symptoms, one in five people aged between 18 and 34 who do not suffer from chronic medical conditions reported cases of long COVID after their initial infection.

The Journal of the American Medical Association looked at a range of research that found many people have experienced prolonged effects of COVID-19, even if they only had mild cases. Yet there's little information to help doctors as they try to care for these people or plan for their future health.

Question 4

Sufferers talk about 'brain fog' – what does it mean?

Physicians and scientists are learning more about how COVID-19 impacts organs outside of the respiratory system, such as the brain. One in particular is becoming known as 'COVID-19 brain fog'. 'Brain fog' is not a medical term, but it's a term commonly used to describe a feeling of memory loss, or difficulty focusing or thinking clearly. Though it can manifest in different ways, the reports are concerning. The New York Times documents a nurse who can't remember what patients say once she leaves the room, one vascular medicine specialist has lost chunks of time from his memory (he couldn't recall 12-day vacation weeks earlier), and a lawyer can't recognize her own car.

This brain fog can have detrimental impacts on everyday life. The lawyer who spoke to The New York Times had to return a foster dog she'd taken in because she couldn't trust herself to take care of a pet in her mental state. It affected her work life drastically, to the point where she had to stop work until she recovered.

In August, France's University of Paris had found that around 34 per cent recovered COVID-19 patients complained of memory loss. Another 28 per cent said they had difficulty in concentrating on the work they did and around 31 per cent reported sleep disorder.



The French study said these symptoms persisted for up to four months after recovery from COVID-19. That study was conducted on a relatively small group of 120 COVID-19 survivors. Another study found that though COVID-19 is considered primarily a respiratory illness, the virus also attacks the brain as was highlighted in research by experts from the John Hopkins University. Researchers have found indications that the coronavirus infects the brain to make copies of the brain cells to “steal” away oxygen and starve the brain cells to death. This leaves the patients with headache, confusion and delirium.

Researchers have underlined that these symptoms are more common among patients in the days immediately after they were discharged from hospital.



How can I report on this issue?

1. Working on stories to humanize the long haulers

Despite the uncertainty surrounding their long-term health, long COVID sufferers or long haulers are looking for ways to regain control of their bodies and get back to how they used to feel. Many patients, particularly with chronic fatigue syndrome, say they aren't believed and are made to feel like they're faking their symptoms by both friends and doctors.

The shame and stigma associated with it can be crushing and hurtful and may even result in depression. By giving a voice to individual long haulers, they would be able to share stories, advice and offer words of comfort to help each other cope. These stories, in turn, could have ripple effects in making employers become fully aware of long COVID and provide long-term sick leave and financial support to their employees who are faced with debilitating symptoms. In terms of public interest journalism, these stories could also help advocate for the definition of recovery from COVID-19 to be based on criteria that extend beyond just testing negative for COVID. People's symptoms, too, should be considered.

2. Giving coverage to groups advocating for long COVID sufferers

Long term sufferers have formed groups on Facebook to put pressure on governments to recognize their needs and to raise awareness among the general public and employers so that people with this condition are not discriminated against. By giving coverage to such groups, journalists can help raise awareness of long COVID. As journalists, we can help support these COVID long haulers who are pushing for respect, research, and support from the general and medical community.

3. Language is important

Words such as 'post', 'syndrome' and 'chronic' risk delegitimizing suffering and that will make it harder for people to access care. Such terms also carry assumptions about the condition's underlying physiology that have not yet been properly investigated. Long COVID, by contrast, states clearly that people's experience of illness after infection is long.

Make sure you understand the impact of the words you choose. Use language that does not discriminate against anyone and label them as COVID 'spreaders'.

So far, we don't have any evidence that people with long-hauler COVID are contagious. In the many cases where they have been tested, there have not been any detectable viral loads. Long COVID is the result of being previously infected, and not the result of having an ongoing infection.

4. Keep up to date with the science

Stay up to date and learn about SARS-CoV-2 and COVID-19 so that what you write or say is accurate and does not contribute to myths and misconceptions that can hinder prevention efforts. Help people to understand actual risks versus their fears, rumours and stigma.

You have a duty to keep your audience informed so they are aware of the threat and can also better care for their friends and families who may be experiencing it.

5. Continue reporting on the virus and its impacts even though it may feel the threat has passed

There is a huge amount of information available about COVID-19, and therefore a risk your audiences will get communication fatigue and feel the threat has passed. Find new ways to keep them listening and talking about the virus and COVID-19 without creating panic. Remember, the threat has not passed for COVID long haulers.

6. Remind young adults that they need to take COVID-19 seriously

More young adults under the age of 30 are testing positive for COVID-19. While the numbers may be due to expanded testing and detection, we also know that many young people are not physical distancing as they should be.



Experts are urging young people to take the virus more seriously and you can remind your young adult audience of this. Even when they have mild symptoms or no symptoms at all, young adults can easily spread the virus to older adults and those with underlying health issues — who are at higher risk for serious complications from the virus.

And while young adults are less likely to develop severe infections, some of them do develop serious complications and require hospitalization, even intensive care that can lead to long COVID. Younger people with diseases like asthma, obesity, immune disorders, diabetes, liver or heart conditions are also at greater risk of severe COVID.

