



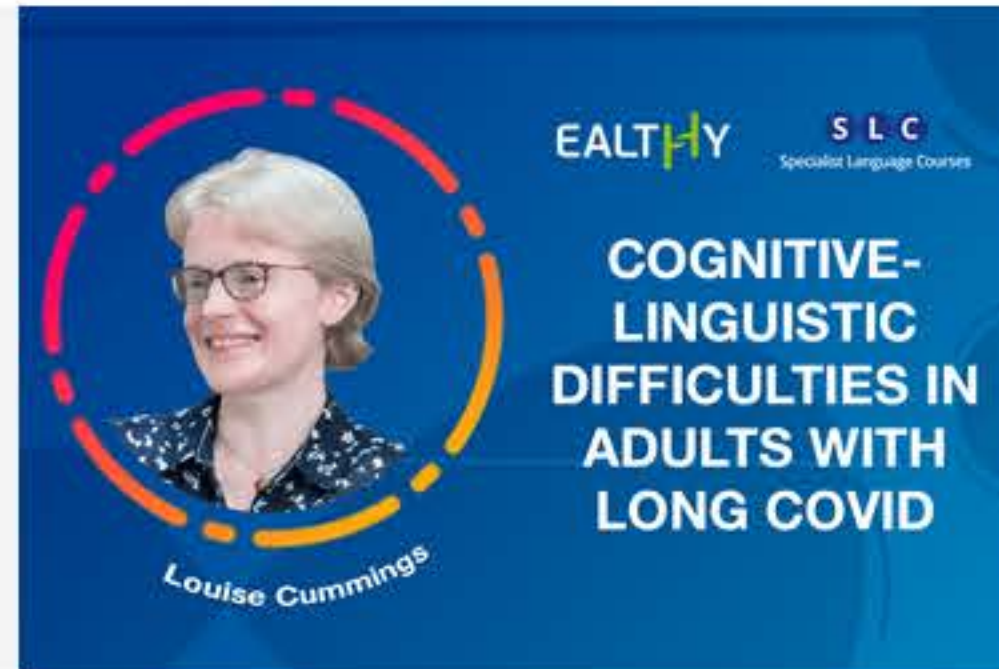
< [Back to Research](#)

Research

Long COVID: Understanding the Legacy of the COVID-19 Pandemic

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We have heard a lot in recent months about how we must learn to “live with” COVID-19. Quite apart from what it means to “live with” a virus that between 13 March 2020 and 19 August 2022 was reported on the death certificates of 203,159 people in the UK, there is the question of what it means for someone to live with Long COVID. For the 2 million people in the UK (3.1% of the population) who have not made a good recovery from the SARS-CoV-2 virus (ONS, 2022), living with COVID is an ever-present reality. For the last two years, I have studied people who have been left struggling with the long-term effects of COVID-19. The language and communication problems of these individuals are significant and profoundly impact the quality of their lives. My particular interest in this population of adults has been on their cognitive-linguistic difficulties. (It should be noted that children can also experience Long COVID.) In this article, I describe some of these difficulties and examine their impact on the lives of the people who experience them.

The post COVID-19 condition

The term “Long COVID” was coined early in the pandemic to capture the persistent and debilitating symptoms that many people were still experiencing several weeks after infection with SARS-CoV-2. Government assurances at the beginning of 2020 suggested that COVID-19 would be a relatively mild, self-limiting illness that would cause cold-like symptoms in most people. Initially, that appeared to be the case – many people who became ill in March and April 2020 reported an illness that was managed at home with a return to work after 2 or 3 weeks of recuperation. Only then did it become apparent that the SARS-CoV-2 virus has a sting in its tail. Many people who returned to work, even managing to work in some cases for several weeks, then experienced a significant relapse in their health. For some, this relapse involved a return of earlier symptoms that they thought had resolved. For others, there was the onset of new symptoms that were not present during their acute infection. In all cases, these relapses necessitated further periods of sick leave. Sadly, for a significant number of people, they have not been able to return to their original work roles, even with phased returns and other occupational health supports, some two years from the start of their illness.

The group of symptoms labelled “Long COVID” is referred to as the “post COVID-19 condition” by the World Health Organization (2021). The WHO defines this condition in the following terms:

“Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.”

Cognitive dysfunction in Long COVID is commonly referred to as “brain fog”. The term captures a group of cognitive-linguistic difficulties that have a surprisingly high prevalence in people who have developed COVID-19. Davis et al. (2021) recorded cognitive symptoms, including problems with memory, in approximately 88% of adults of all ages in a study of 3,762 people with COVID illness lasting over 28 days. In a survey that examined 11 language difficulties in 973 adults with Long COVID, problems in all but two of these difficulties were reported in over 50% of respondents. The most common problem was word-finding difficulties which were reported by 93.1% of respondents (Cummings, 2023). Problems with language and cognition often only become apparent after physical symptoms have improved and people attempt to resume work duties and other roles. For many people with Long COVID, these difficulties are likely to have been present from the onset of their illness, but they were masked by the severity of respiratory, cardiac, and other symptoms. Debilitating fatigue is a universal feature of Long COVID, and it can also complicate the presentation of cognitive-linguistic difficulties. Whether a persistent symptom from the acute infection or a symptom of new onset, brain fog and its attendant difficulties significantly compromise daily functioning in people with Long COVID, as we will see below.

Exploring cognitive-linguistic difficulties

Difficulties with language and cognition that are routinely reported by people with Long COVID prompted me in October 2020 to start recording these adults. To date, I have analysed the language of 105 adults with Long COVID, with data from 92 adults assessed alongside the performance of healthy adults and adults with ME or Chronic Fatigue Syndrome (Cummings, 2023). Among the 12 tests administered to these adults were tasks examining immediate and delayed verbal recall, category and letter fluency, sentence generation, and confrontation naming. To capture the influence of cognitive processing problems on language, the test protocol also included several discourse production tasks. These tasks differed in their cognitive demands on participants. The least challenging was simple picture description where the demand on memory was low. More challenging discourse production tasks included narration based on a sequence of black-and-white line drawings and storytelling using a well-known, fictional narrative. These tasks permit the examination of high-level cognitive-linguistic processes such as use of inferences, attribution of complex mental states to story characters and sequencing of events based on temporal and causal relations. While time-intensive in terms of administration and scoring, these tasks are most likely to reveal the difficulties of this group of adults whose structural language skills and auditory verbal comprehension are relatively intact for the most part.

The results of these assessments demonstrated that adults with Long COVID had significantly poorer performance than healthy participants in immediate and delayed verbal recall, category fluency (a test of lexical generation) and letter fluency (a test of executive function). Discourse informativeness was also compromised. Adults with Long COVID typically displayed reduced informativeness during discourse production. They tended to omit essential information, use less informative superordinate terms like animals over more informative words like sheep and cows, and produce repetitive, vague language. These informational deficits were not predicted by their structural language skills – these adults could access a full range of grammatical and lexical structures. However, they could not use their strong structural language skills to produce informative discourse. The difficulties of these adults with Long COVID are quite unlike the problems seen in a primary language disorder like aphasia, although aphasia is one of the neurological sequelae of severe COVID disease (Piftits et al., 2020). Instead, the language difficulties of these adults appear to arise from their cognitive processing problems. As such, they are more akin to a cognitive-communication disorder, albeit a disorder that is more subtle in nature than the type of cognitive-communication difficulties often seen in adults with traumatic brain injury and neurodegeneration.

The communication impact of Long COVID

In describing the cognitive-communication difficulties of adults with Long COVID as subtle, this should not be taken to imply that these difficulties are minor in nature. They are not. The adults with Long COVID and brain fog whose language was assessed in Cummings (2023) had an average age of 49.1 years; the 973 adults who participated in the survey had a mean age of 47.4 years. Adults with Long COVID are mostly of working age. Many of them had demanding professional roles prior to developing COVID-19. For high-functioning individuals in demanding roles, even the more subtle form of cognitive-communication difficulty that these adults are experiencing has had a devastating impact on their lives and careers. The survey revealed the extent of that impact. Only 22.8% of respondents stated that they met the communication needs of their job following COVID-19. This resulted in many people being unable to return to work. While only 2.4% of survey respondents were not working due to disability before their COVID illness, this increased to 32.5% after COVID-19. The impact of COVID-related communication problems was equally devastating on the social relationships and family lives of these adults. Following their COVID illness, only 12.6% of respondents strongly agreed with the statement ‘I stay in touch with family and friends’, while only 13.1% strongly agreed that ‘My role in the family is the same’. Perhaps the clearest insight of all into the impact of COVID-related communication difficulties on the lives of adults with Long COVID can be gleaned from the personal narratives of these adults. A 44-year-old woman who was 10.8 months post onset remarked:

“Long Covid and my communication problems have affected every part of my life, they have taken away everything I had [...] This has had a massive impact on my life. It has taken away my purpose and identity.”

This statement reveals the true cost and largely hidden legacy of the COVID-19 pandemic.

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