

After Biden claims that “the pandemic is over” and “everybody seems to be in pretty good shape”

## Long COVID and ME/CFS patients denounce Biden in protest outside White House

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19 September 2022

Dozens of demonstrators affiliated with the patient advocacy group #MEAction gathered Monday on the sidewalk in front of the White House, chanting, “Biden lied, we died, ME treatments now!” and “The pandemic is not over! Biden’s lies are costing lives!” They were joined online by thousands more who could not travel due to their condition. However, there was hardly a mention of the event in the mainstream press. One had to turn to social media to gather news on these developments.

The protest, organized by Long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) patients, had serendipitously been scheduled for September 19, one day after the airing of President Biden’s interview on CBS News’ “60 Minutes,” in which Biden declared, “the pandemic is over.” He added, “No one’s wearing masks. Everybody seems to be in pretty good shape.”

Biden’s statements amounted to a slap in the face to tens of millions of Americans who have had their loved ones suddenly taken away from them due to COVID-19 or suffer from its debilitating consequences and have been essentially ignored by the political establishment. Laurie Jones, executive director of #MEAction, shot back at Biden, saying, “Not only is the pandemic not over, the disabling of millions of Americans from Long COVID and ME/CFS has become a national emergency.” (Jennifer Brea, co-founder of #MEAction, gave this TED talk to contextualizes life with ME.)

Indeed, the pandemic is far from over even after nearly 1.1 million Americans have died from COVID-19. Between 400–500 Americans continue to

die every day, the equivalent of the deaths suffered in the September 11, 2001, terrorist attacks every week. During the pandemic, COVID-19 has consistently been the third leading cause of death, including in 2022, as it has already killed more than 225,000 and counting.

With the fall and winter seasons approaching, experts fear that a simultaneous surge of COVID-19 and the flu will have major consequences on the population and health systems which have already been broken by more than two years of incessant waves of COVID-19.

Debilitating Long COVID already affects upwards of 4 million working-aged Americans, while as many as 12 million Americans have such severe Long COVID that they would likely meet the diagnosis for the complex, chronic disease ME/CFS, which often leaves patients unable to work and participate in daily life. Currently, the mechanism for both diseases is poorly understood and no therapies or medications are approved to treat the conditions.

Even before the COVID-19 pandemic, somewhere between 0.84 to 2.5 million Americans were affected by ME/CSF at a cost of \$24 billion annually to the economy. Across the globe, an estimated 15–30 million, including women, men and children, are suffering from ME/CFS, with roughly 75 percent unable to work and 25 percent so severely affected that they were housebound or bedbound.

The #MEAction group, which calls themselves the “millions missing,” explained their precarious social position in their communities:

Unable to work, socialize, or appear in public spaces, we are missing important parts of our lives. We are missing careers, missing time spent with family, and for the most severe, we are missing ordinary moments like going out in the sun, reading a book and socializing with a friend.” They also note that “millions of dollars are missing from government-funded research.” This is further compounded by “millions of doctors and other healthcare providers missing the medical education they need to diagnose and care for people with ME.

The ranks of those suffering from symptoms related to ME/CFS have been compounded several-fold by the preventable COVID-19 pandemic, as Long COVID can present similar symptoms to ME/CFS and is believed to have a similar pathophysiology. According to the *Financial Times*, debilitating Long COVID may already impact up to 100 million people globally. Just in the US, the impact on the economy has been estimated at close to \$750 billion per year by Harvard economics professor David Cutler.

Yet spending to study ME/CFS has languished. Though the prevalence of ME/CFS is comparable to HIV/AIDS, for which the National Institutes of Health (NIH) allocated close to \$3 billion in funding between 1995 and 2014, on average only \$5 million in annual funding was allocated towards studying the causative factor and treatment for ME/CFS. In 2017, funding was raised to a paltry \$15 million per year.

As the Brookings Institution noted in their most recent report, although Congress has dedicated \$1.15 billion in NIH funding to study Long COVID, these grants are challenging to access, in line with the government’s poor record on supporting such necessary work. The experience with supporting research and funding for ME/CFS is but a cautionary tale.

CNN’s Morgan Stephens was the sole reporter on the scene yesterday taking interviews with demonstrators and posting them on her Twitter account.

One moving statement by protest organizer Terri Wilder was directed towards President Biden, saying, “If you survey the people across the country and you ask them, ‘Is the COVID pandemic over?’ the majority

of the people will say, ‘No!’ If you ask people if we should still be wearing masks, the majority will say, ‘Yes.’ To say that [the pandemic is over] ... it is mind blowing that you said that! We are here today to demand that you declare ME and Long COVID a national emergency.”

In another shot, Stephen asks Gabriel San Emeterio, “You have a chronic illness, you are tired, bedbound, what does it mean to be out here physically?” Gabriel answers, “I’m putting my body on the line, literally. We are putting our bodies and our lives on the line. We are all going to crash, we are all going to worsen our symptoms. Our baselines of functioning might be lower permanently or for a long time.”

At one point, the protesters lay on the ground in a death pose, die-in version of a sit-in, repeating in unison, “History will recall, Biden did nothing at all!”

At the end of the hour-long protest, Stephens noted that about two to three dozen people had attended the demonstration to bring attention to the inaction on Long COVID and ME/CFS, explaining how taxing even such an event can be on them. She then told her viewers she had to return home to rest as she too suffers from Long COVID.



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