

“Elimination approaches have led to a massive increase in life expectancy, economic growth, and quality of life in many countries for decades”

Long COVID advocate Dr. Elisa Perego speaks on the pandemic and the need for global elimination

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10 October 2022

The World Socialist Web Site recently interviewed leading Long COVID advocate Dr. Elisa Perego, who first coined the hashtag #LongCovid in May 2020 after her experience with prolonged symptoms. Dr. Perego describes the patient-led efforts to study and educate others on Long COVID, the criminal policies implemented by numerous world governments, and the significance of historical struggles to eliminate and eradicate infectious diseases.

Evan Blake (EB): Can you tell us a bit about your background and research?

Dr. Elisa Perego (EP): I am a researcher from Italy. I also lived in the UK and Austria for study and work. As a researcher, I work across different disciplines. My background is interdisciplinary. Broadly speaking, I study social inequality, health and disability in present and past societies. My PhD is in archaeology. I was a Marie Curie Fellow at the Austrian Academy of Sciences in Vienna in 2017-19. I have also worked on human- and gene-environment interactions, climate change, and people’s responses to crises in ancient societies.

I am a person living with Long COVID and other chronic diseases since childhood. I am currently contributing to policy, research and science communication on COVID and Long COVID. I took part in the landmark WHO meeting of August 2020, which openly recognized the long-term health effects of SARS-CoV-2 infection. I tweet at @elisaperego78 about Long COVID, patient advocacy and infectious diseases in our pandemic time.

EB: What was your experience like at the start of the pandemic? My understanding is that you actually coined the hashtag #LongCovid on May 20, 2020, after your own symptoms didn’t go away. Can you share more about this? What was the response like initially and how has awareness of Long COVID developed since then?

EP: In early 2020, I was in Lombardy [Italy], the first COVID epicenter outside China. As a chronically ill person and a researcher, I was alarmed by the news about the emergence of the novel coronavirus. In January and February, I was following the growing scientific evidence closely. And then Lombardy was hit very hard. Initially, the situation was like, you know, sensing a storm that you feel is coming.

Soon, it became chaotic, tragic. Our health care system couldn’t cope with SARS-CoV-2. “Silent” community transmission wasn’t detected in time. The world saw the footage of Bergamo. I was quite ill with acute

COVID, but I could not receive any meaningful medical support. I was triaged by phone, to no avail, because health care in my area was under duress.

I survived the acute pulmonary phase, but the disease progressed over time, with new symptoms and clinical signs appearing, or returning. Symptoms are too numerous to list. My cognitive impairment was severe, but I was trying to keep up with the emerging scientific data as much as I could. I was on Twitter. I could only read or write little bits at the time. I was writing privately to people about this long-term COVID illness. Long COVID is a contraction of similar terms I was using to describe my experience with COVID. This was in March and April 2020.

In May 2020, I suffered from a major relapse, with multi-system, cardiovascular and cardiopulmonary symptoms. My oxygen saturation started to drop again. I was in month three. I had the opportunity to discuss with a health care professional the possibility of clotting in my lung, which I had been concerned about. Micro-clotting and vascular damage in the lung and other body parts were being flagged as key features of severe acute COVID. But they weren’t discussed so far into the disease course.

This relapse sealed for me that we were dealing with a prolonged, severe, potentially life-threatening disease, with a strong cardiovascular component. There was also discussion, in Italy, about COVID tests that remained positive for weeks. I highlighted this in the #LongCovid hashtag tweet on 20 May 2020. Long COVID was almost immediately adopted by other COVID survivors, including creators of online support groups in the UK and many advocates. The term went viral. Professor Felicity Callard and I tell the story in “How and Why patients made Long Covid.”

I simplified the story a lot. I just want to add that I never recovered. Problems like relapsing–remitting hypoxemia, arthritis, coagulopathy and cardiovascular disease never left. Some actually became even more prominent, especially in late 2020 and early 2021. I suffered from a severe cardiopulmonary event in early 2021. I have been sharing these data across the networks of advocacy and beyond.

Cognitive impairment has improved, but I am still very affected, especially with memory loss. I am too ill to have a normal job for now. I mention my health status because I want people to know that many with Long COVID are suffering from severe disease with no appropriate support. This is despite the knowledge we already had in 2020.

Some of us have been trying to raise the alarm about the severity of the situation, in publications, in policy, but response has been slower than it should have been.

There is a lot of research available now, but we really need to translate knowledge into treatment. The costs of delays are horrendous for individuals and society alike. Lombardy has been hit by COVID wave after wave. This has greatly impacted people's ability to obtain good medical care, including myself. More death and illness have come, too.

Italy and many other countries formally recognized Long COVID in 2020-21 and are producing guidelines. Formal recognition is important. I am happy to have contributed where I could. Long COVID is now a global phenomenon. It goes beyond medicine. It intersects with disability activism and the history of patient-led movements like HIV/AIDS. Billions are being put into new research. But access to care remains patchy. Communication of Long COVID by policymakers remains very inadequate, in my opinion. People are often unaware of the real risks of SARS-CoV-2 infection.

I think we need an in-depth, independent investigation into the pandemic response worldwide. We knew in January 2020 we were facing a potential pandemic driven by a SARS virus. This was published in the top scientific journal *The Lancet*. We knew about Long COVID in 2020. Things have gone terribly wrong. Millions of people have died. Huge numbers have experienced Long COVID. How many are now chronically ill and disabled?

I am a very reserved person. Initially, I turned to my Twitter account—at the time I had something like 300 followers—because I could not believe countries were so flippant with their COVID responses. This was unthinkable, when I was experiencing the horrors of an unleashed SARS-CoV-2 spread. Lombardy was hit before Italy's national lockdown. I was interacting, initially, with international accounts, trying to convey the catastrophe of Lombardy. I was very ill at the time.

Little by little, I started to tweet about COVID as a prolonged disease. There were other people going through this, and we built a connection. I am proud to have built collaborations that contributed to research and the formal recognition of Long COVID, starting from those early Twitter interactions, when we were all so ill. But why was it up to patients to fight for recognition, while many policymakers and “experts” were minimizing the dangers of COVID?

EB: Since 2020, Long COVID advocates have referred to the pandemic as a “mass disabling event,” and we're seeing that confirmed more and more each day with studies proving that COVID-19 can damage nearly every organ in the body. Can you speak to this issue, and what concerns you most about the implications of mass infection for long-term debilitation? How do you see this “mass disabling event” impacting society more broadly at present, in the next 5 years, 10 years and longer-term?

EP: Yes, the pandemic is a mass disabling event. We in the early red zones were seeing and hearing of people not recovering. People terribly sick from COVID. People taken to the hospital and never returning. Not just a few. Many. We saw and experienced the reality of the disease, often with no medical care. This is why we understood the magnitude of the disaster so early. As you say, the evidence is now crystal clear. There is enormous biomedical research on acute and Long COVID. COVID is now one of the most studied diseases in medical history.

SARS-CoV-2 is a very dangerous, contagious virus. Vaccination, right now, might stunt some of the worst effects, but it is not perfect. The virus continues to evolve. Many people were infected before they could be vaccinated. This includes children. Many people have been reinfected. Some are faring worse on a new infection. We have been reporting from the grassroots community that many living with Long COVID suffered a setback on reinfection. There is growing evidence of COVID's impact on pregnancy and the unborn.

We don't fully understand how ongoing reinfections will play out on a population level, how bad this is going to be. As a patient and a researcher, I am very concerned. The future is not written, sure. It will depend on how the virus evolves, if we develop better vaccines, and if governments will go for hard containment and full airborne prevention at some point.

But what we have now is already very concerning. Long COVID is not rare. Health care systems are under distress. Care for diseases that are normally treatable is already reduced. It's my own experience, among others. Many with Long COVID have been left with no support, even with life-threatening disease. The most vulnerable are hit the hardest, but even the wealthy are not spared. We don't have exhaustive reports, to my knowledge, of what's happening with Long COVID in areas of the world where surveillance is less strong.

In the worst case scenario, we could reach a tipping point, where only the well-off will have access to good, or even basic medical care as a norm. This could happen even in countries with a strong tradition of public health care, like Italy or the UK.

Many infected with SARS-CoV-2 have a new disability, or health condition, they didn't have before. We don't know exactly how many could have sub-clinical pathology, such as barely symptomatic or asymptomatic cardiovascular disease. They might not even be aware of it. But it's a vulnerability. It could lead to severe disease or premature death in the future.

We know viruses have far-reaching effects on human health. We know about diseases caused or connected to viral and other infections, like ME/CFS, post-Ebola syndrome, or the long-term sequelae of the first SARS, which I often call Long SARS. We know many SARS survivors were ill for years or never recovered. This is a huge red flag for SARS-CoV-2.

Severe disease can also develop decades after an infection, like with some cancers linked to viral infections, or post-polio syndrome, and, of course, AIDS, in the context of chronic, untreated HIV infection. Another example is multiple sclerosis, which is being increasingly linked to infection with the Epstein-Barr Virus (EBV). The mechanisms through which viruses can affect human health are multiple and not completely understood.

We don't fully grasp the implications of this with COVID and multiple exposure to SARS-CoV-2. The precautionary principle should be applied as a matter of urgency. We are going to face this looming crisis with an increasingly broken health care system and mounting disability from COVID.

I studied disease and disability in the past. You can track changes in human health across space and time in human remains, like bones and teeth, and through historical sources. Health is not a given. Inequalities and political choices play a big factor in shaping human health. This is happening with this pandemic, too.

EB: Since the Omicron variant was detected last November, almost every world government has scrapped nearly all remaining mitigation measures, including mask mandates, testing, contact tracing, isolation and quarantine guidelines and more. At the same time, they've manipulated data to falsely portray SARS-CoV-2 as “endemic” and essentially harmless, while millions more people have died and tens if not hundreds of millions more have been debilitated with Long COVID worldwide. What are your thoughts on what has happened during the Omicron surge and the present situation we're now in?

EP: We should have contained Omicron. We knew it could go beyond prior immunity, to an extent, soon after it emerged. And not everyone was vaccinated or boosted, even in “first world” countries. People have suffered and died needlessly. We have now experienced new waves with variants like BA.5. There is no evidence SARS-CoV-2 will stop evolving into variants of concern any time soon. Reinfections are common and are

not harmless.

Even countries that were maintaining safety measures, such as indoor masking, like Italy, have been dropping them. I find this dark, concerning. The monkeypox international outbreak has also emerged as a new global emergency.

Early response to monkeypox has been slow and plagued by some of the same mistakes we saw with COVID, in my opinion. Other pathogens like the poliovirus and the Ebola virus are reemerging in countries that eliminated or contained them, and the far-reaching implications of this remain to be fully appreciated. There has been a significant outbreak of West Nile disease in north Italy. I can't even finish answering this interview and a new outbreak, or a new problematic pandemic policy, makes the headlines!

We can't live a full, healthy life this way. We shouldn't accept this.

EB: You had a significant thread in June which went viral, in which you shared numerous papers on efforts to eradicate different pathogens, including smallpox, polio, rinderpest, gonorrhea and more. I think the massive support you received for this indicates that in contrast to the official policies, many people want to fight the COVID-19 pandemic and see this virus eradicated. Can you elaborate more on this, including your thoughts on previous elimination-eradication efforts and whether we can and should fight to eliminate SARS-CoV-2 globally?

EP: I was happy my thread on eradication efforts went viral! I think people are longing for the pre-pandemic world. They don't want to "live with COVID." But they are also scared, and they are not being informed openly about things like airborne transmission and Long COVID. If people were fully aware of the far-reaching implications of COVID, they would be more vocal about containing SARS-CoV-2 and asking for care. This is one reason why policymakers speak so rarely about Long COVID, in my opinion.

I simplify a lot here. But the literature and history of public health show that we fought hard, relentlessly, against infectious diseases with the weapons at our disposal. Vaccination for smallpox, polio or measles. Clean water and sanitation with cholera. Antiretroviral drugs and various safety measures with HIV/AIDS. It wasn't immediate. It wasn't easy. People had to fight. Not all of these diseases disappeared. But we did fight.

Zero COVID has been described as "impossible," "zealotry" or a limitation of "freedom." It has been ideologically associated with the political landscape of countries like China. But Zero has been the goal for most diseases. Zero is the goal of public health. It's the visionary approach that led to the eradication of smallpox and the elimination—or drastic containment—of many diseases across the world. Zero doesn't mean elimination in two days! Zero is the fight, the scope, the real commitment to bettering human health.

Elimination approaches have led to a massive increase in life expectancy, economic growth and quality of life in many countries for decades. In many of our privileged societies, we have largely forgotten what it was like having little children dying from infectious diseases as a norm. People going to sanatoria for tuberculosis. Iron lungs for polio survivors. Cholera, which they nicknamed the Blue Death from the skin colour of the very sick.

I think no one would choose going back to something even remotely similar if they could really decide freely.

EB: What are your thoughts on the fact that China has repeatedly eliminated SARS-CoV-2, including most recently the highly contagious Omicron BA.2 subvariant, using basic public health measures? How can we learn from and improve upon their "dynamic Zero-COVID" approach?

EP: I think a concerted effort could have eliminated or at least hard-contained SARS-CoV-2. Other countries apart from China did it. Instead, many in positions of influence have devised or embraced ideologies like "endemic COVID," "living with COVID" or "herd immunity" via natural

infection. Namely, keeping the virus here with imperfect or minimal solutions to control its spread. I'm concerned about these approaches being applied beyond COVID in the future. I'm concerned about the rewriting of the rules of public health. Everything is "mild" and we should accept "living with it" as a matter of "personal responsibility."

I think we can—and must—fight SARS-CoV-2 with the best weapons at our disposal. This doesn't mean a "draconian lockdown" as some depict Zero COVID! We can fight for clean air. We cleaned the water. We built sewers. We aren't urinating in the streets as a "centrist" policy. We could inform people openly about how COVID works. We can deliver top epidemiological surveillance. Provide sick pay and disability support. Develop fine-tuned airborne prevention. We can offer high-quality masks and tests for free, to those in financial need especially. Make health care and other shared settings super safe. Put top resources into next-generation vaccines, diagnostics and treatments, which should be available to all people throughout the world. Practical responses might be context-specific, for example in different countries, according to local needs and resources.

Some of these tools are already available to the elite and the well-off. The others are left behind. There is a lack of political will. Not a lack of technical or scientific expertise, or money. Aren't we paying for a few wars and tax breaks for the super rich? We went to the Moon in 1969.

EB: From the beginning of the pandemic, the WSWS has stressed that it's not simply a medical crisis, but fundamentally a political, economic and social crisis that can only be resolved through globally-coordinated action. As socialists, we've argued that world capitalism is incapable of mounting such a response because of the division of the world into rival nation-states and the subordination of public health to private profit. Can you comment on this and your thoughts on the broader political, economic and social issues that the pandemic has raised?

EP: I broadly agree from a social and historical viewpoint. I think the pandemic now is both the product of the uber-capitalism of the last decades, and—so far—an accelerator of it. It's the age of billionaires going into space, while people are mass infected with a SARS virus on Earth. COVID itself provides a framework for more profit at many levels. Concierge care for the rich. Privatization of health care. The market for vaccines and antivirals. Just a few examples. "Endemic" COVID is quite convenient for a few, isn't it?

It goes beyond politics, of course. It's a rewriting of what a meaningful life—a meaningful human being—is. Who deserves to live healthy and who isn't valuable enough to be protected from COVID. Don't get me wrong. The dehumanization of marginalized groups has been happening for ages. It's predating the pandemic. But it's now accelerating. We see the signs.

The current "endemic" policy is leaving the most vulnerable to fight COVID alone. The "old and sick" have been singled out, almost triumphantly sometimes, as the only ones at risk from SARS-CoV-2, to reassure the rest. There are reports that the "black code" has been used to let people die when health care was overwhelmed. Ambulances are reported not arriving in time if you have a myocardial infarction or a stroke—on a large scale.

People are being primed to accept mass infection and chronic illness for little, short-term gains. I'm speaking about the normalization of ill health on a scale that we, in our relatively privileged societies, have forgotten. I'm speaking about the increasing devaluation of people that are portrayed as a burden to the system. But where does this slippery slope end? Even the president of the United States had COVID. His private health status was displayed in the media as a "teaching moment for the nation."

Pandemics are history-making events. I don't know how it's going to end. I still hope we can make something of it. Recognition of Long COVID and viral onset diseases is at least a step forward. I said a few times that Long COVID was going to change medicine. I will keep fighting for this with allies and the community despite severe illness and

so many political hurdles.

EB: Thank you for your thoughtful comments and for taking the time to speak with us.

EP: Thank you.



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