As Someone With Long COVID, I’m Terrified of What Could Happen to the Affordable Care Act

I fear that many Americans – including myself – may soon be deprived of the accessible, affordable healthcare we desperately need.

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It’s not an exaggeration to say that the Affordable Care Act (ACA) saved my life.

Nearly 15 years after it became law, this important piece of legislation continues to help keep me and many of my loved ones alive. Before the ACA, many members of my family – including myself, my children, and some of my siblings – had to pay more expensive premiums, were shuttled into state-run high-risk pools, or were unable to get insurance coverage at all, mainly because we had chronic or recurring health conditions.

As someone with long COVID, I’m terrified right now. Healthcare access is becoming more uncertain as we in the U.S. prepare for a shift in the federal leadership. With Donald Trump returning to the White House – who has long had the ACA (commonly known as Obamacare) in his crosshairs – I worry that my family will be among the millions of Americans who could lose access to the vital healthcare services we need.

In addition, millions of Americans lost healthcare coverage as a result of the Medicaid unwinding that occurred after the Biden administration ended the COVID-19 public health emergency. Many others have lost their jobs – and the health insurance that went with it – as a result of long COVID or other health issues. In our current situation, I do worry about whether Democrats can – or will – do anything to fight back if Trump does move to make big cuts to the ACA.

My biggest fear? That core elements of the ACA will be cut or changed significantly under Trump. These include prohibiting insurance companies from penalizing or denying coverage to people with pre-existing conditions, expanding Medicaid coverage in most states, requiring coverage of certain preventive care, and allowing young adults to remain on their parents’ insurance until age 26. Rolling back these requirements would limit or totally eliminate access to healthcare for millions of Americans, including those who need critical healthcare services the most.

A particular concern for those with a COVID-19 history

Healthcare should be a basic human right, but unfortunately it isn't treated like one in America. Instead, it has often been a luxury only available to those who can afford it. The ACA – while far from perfect – went a long way to help making healthcare more accessible to many more Americans, including people like me and my family who had been forced to go without medical care.

The ACA is popular with Americans of all party affiliations, and Trump and his cohorts would surely face strong pushback if they try to eliminate it. Rather, I think it's likely that they will change or eliminate core aspects of the ACA, greatly weakening it to the point where it no longer helps many Americans access healthcare.

I'm particularly concerned about any changes to the rules for pre-existing conditions, especially given the high prevalence of long COVID. Insurance companies use the term "pre-existing condition" to mean any health issue or condition you already had prior to obtaining insurance coverage.

According to Jen Kates, Senior Vice President and Director of Global Health & HIV Policy at KFF (a nonprofit health policy research, polling, and news organization), if lawmakers eliminate the pre-existing conditions protection, we'd return to scenarios common in the pre-ACA days. In that time, "insurers would not be required to offer insurance to someone with a pre-existing condition, or could offer insurance but charge higher rates, or could offer insurance but not cover a particular condition," Kates told The Sick Times.

As someone with long COVID, I worry that health insurers could start considering long COVID as a pre-existing condition, along with conditions like cancer and heart disease. Kates said Congress would need to take action to make exceptions for specific conditions – a move she considers unlikely in the case of long COVID, particularly if exceptions aren't also made for other common conditions.

In addition to living with long COVID since early 2020, I'm also a stroke survivor, was born with a congenital heart defect, and have other health conditions. In other words, I'm the type of person that insurance companies would gladly drop if they could.

The prospect of losing healthcare access triggers a feeling of dread and déjà vu for me. Prior to the Affordable Care Act, my family went years without health insurance – which meant we also usually went without healthcare. Because my children and I all had medical issues, insurance companies wanted to charge us exorbitant rates or refuse to insure us at all, and the law at that time protected them. Even when we were able to get health insurance, the insurance companies could refuse to cover anything related to what they deemed a "pre-existing condition."

During that period, I once literally begged a surgeon to schedule surgery for my son. The office refused to do so, unless we proved we were able to pay the full cost of the surgery out of pocket and could provide an immediate 50% deposit upfront.

Mostly, though, we just went without medical care at all. One of my sisters now needs a double lung transplant, partly because she went years without any medical care at all in the pre-ACA days. My other sister has advanced multiple sclerosis, and she too also went years without any medical care.

An unknown future for the ACA

For those of us with serious health issues, the fear and uncertainty around our future healthcare access takes an additional toll on our physical and mental health.

Trump is notorious for making spontaneous, erratic decisions and frequently contradicting his own past positions. So it's impossible to predict with any level of confidence what may happen.

But there's good reason to fear that the ACA is at risk, based on things that Trump, Elon Musk, Vice President JD Vance, Speaker of the House Mike Johnson, and other Republican leaders have said – and the fact that Musk and Vivek Ramaswamy are planning to slash government spending, in part by targeting safety net programs.

Some changes to the ACA that experts say could happen include:

- Expiration of subsidies that help many Americans get coverage through the ACA Marketplace. If these subsidies end, premium costs will rise substantially, resulting in millions of people losing their insurance. Several of my immediate family members rely on these subsidies and wouldn't be able to afford their insurance coverage without them.

- Stricter Medicaid eligibility requirements. Republicans have long pushed for work requirements for safety net programs for Medicaid, and more than a dozen states implemented these rules for at least some Medicaid participants during the previous Trump administration.

- End of Medicaid expansion in some states. As part of the ACA, most states expanded Medicaid eligibility, which allowed millions of low-income Americans to get healthcare coverage. But if federal funding is cut, the expansion would be at risk – and in some cases might end immediately due to "trigger laws" in several states.

- Other potential changes: The launch of high-risk pools, the return of "junk" insurance plans, and cuts to assistance programs that help people navigate the insurance enrollment process.

What can we do now?

For all its benefits, the ACA in its current form has major weaknesses, and the challenges of navigating our country's complex health insurance system can be overwhelming. Many people who are eligible for insurance through Medicaid, the healthcare marketplace, or other programs fail to enroll and instead go uninsured.

I would love to see universal healthcare such as Medicare for All, but realistically I know there's no way that will happen over the next four years with the right-wing landscape we have today. The most we can do right now is try to protect the best aspects of the ACA. I encourage everyone to contact their state and federal lawmakers to let them know how important the ACA and Medicaid programs are to them – and specifically emphasizing your concerns about how that would impact those with long COVID.

In addition, it might be helpful to urge them to support initiatives like the Long Covid Research Moonshot Act, which would raise awareness of this disease and provide funding to support research and treatment for long COVID.

Because we have no way of knowing exactly what may happen to the ACA, it's difficult to decide how best to prepare. Over the past two months, my family and I scrambled to take care of as many medical appointments and procedures as possible before the inauguration. I also helped many people navigate the marketplace and the Medicaid enrollment systems, so they could get new coverage (or change to different coverage) while they had the chance, before that becomes more difficult.

Like many people with long COVID, I expect that I'll need treatment for the issues caused by this condition for a long time, possibly for the rest of my life. That's a daunting enough prospect, but the possibility that potential changes to the ACA could mean I may have to try and survive those health challenges with limited healthcare coverage – or no coverage at all – is frightening.

Here are some resources that may help you navigate the current enrollment process:

- Healthcare.gov: The federal health insurance marketplace has assistance available by phone, or in person via an assister or broker (keep in mind that open enrollment for the federal healthcare marketplace ended on January 15, so until it opens again this fall, you can only enroll if you have a qualifying life event or are eligible based on income).
- State marketplaces: Some states have their own specific marketplace websites.
- Medicaid.gov: Links and contact information for state Medicaid agencies.

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