

When You Have MS, Politics is Personal



Since [last summer's](#) failed congressional efforts to repeal many provisions of the 2010 Affordable Care Act (ACA), the hashtag #IAMAPreExistingCondition has peppered countless social media updates.

Current and former cancer patients use it on Twitter, Facebook, and Instagram. Asthma sufferers post it, too. Ditto for people with diabetes, mental health issues and heart ailments.

It was during those debates last summer when I publicly associated myself with this hashtag. Since my July 2014 relapsing remitting multiple sclerosis diagnosis, I have felt extraordinarily blessed to have the ACA already in place so that if my spouse loses or changes jobs, health insurers will not be able to deny me coverage because of my MS.

However, every time a member of Congress proposes a revision to U.S. health care policy that would potentially compromise insurance coverage for those with pre-existing conditions, I experience a surge of anxiety not just for myself, but for my family.

Politics, when it comes to health care, is deeply personal.

The fact that I'm a college journalism lecturer and a serious news junkie—I read three dead-tree newspapers a day (I know... I'm a dinosaur), as well as consume copious amounts of news-oriented programming and social media—means that nearly every time someone floats a health care proposal, I'm almost certain to read about it. Then I watch as patients respond to this news with abject fear. Fear that is embodied by the hashtag #IAMAPreExistingCondition.

Patient advocacy groups ranging from the American Cancer Society to the National Multiple

Sclerosis Society typically issue statements in the wake of these bills, urging lawmakers to protect patients' care. For example, in a June 2018 joint statement, organizations rallied together to state that repealing insurance protections for those with pre-existing conditions would have a "devastating impact" on the estimated [130 million Americans under 65](#) who have illnesses which, in pre-ACA days, would render them ineligible for most health insurance.

Armed with the knowledge that should there be changes to both the ACA **and** my spouse's employment situation, my expensive treatment (regular MRIs, neurological office visits and prescription medicine that costs tens of thousands annually) would jeopardize my family financially. Rescinding pre-existing condition protections would make it legal for insurers to once again discriminate. That's why every proposal feels like a mortal threat. The threat seemed so dire last summer that I invoked the hashtag #IAmAPreExistingCondition so followers on social media would note the proliferation of this hashtag and realize just how many Americans would be affected by legislative changes.

More than a year later, the specter of once again returning to the days of legally rejecting coverage for people who have (or once had) serious illnesses, continues to rear its head.

A recent [New York Times article](#) stated: "In the past year, the Trump administration has... asked a federal court to throw out parts of the Affordable Care Act, including the popular protections for people with pre-existing conditions." While the Republican Senate majority leader has been [quoted as saying](#), "Everybody I know in the Senate-everybody-is in favor of maintaining coverage for pre-existing conditions," 20 governors are currently suing the federal government and asking a U.S. district court to repeal the ACA. Attempts to eliminate legal protections are ironic, given that a late-June 2018 poll by the [Kaiser Family Foundation](#) found that most Americans, regardless of party affiliation, consider preserving health insurance coverage for people with pre-existing conditions to be "very important," and 57 percent of respondents said they or someone in their home has or had a pre-existing condition.

In my little world here in the Boston area, the fear that, in addition to coping with the impact MS has had on my life-like severe heat sensitivity, difficulty scaling stairs, frequent nausea, fatigue, and migraines-I live with the omnipresent threat that the health care which keeps me functioning, which enables me to continue teaching, writing books and articles, and raising my three kids-could be taken away, depending on in which direction the political winds are blowing at any given moment.

#IAmAPreExistingCondition. I don't want to be, but I am. And I'm very, very worried.

Get involved in the conversation. Use #DefendPreEx and #IAmAPreExistingCondition to share your voice.