

SCOUNDREL TIME

ESSAYS

My Brother's Lung Transplant and the Myth of Individual Healthcare Coverage

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So on we go
His welfare is of my concern
No burden is he to bear
We'll get there

– *He Ain't Heavy, He's My Brother* by The Hollies

"It's go time," my niece Amy said, one misty night last May. "He's on his way to the hospital for tests and, if it's a match for sure, he'll be in surgery tomorrow morning."

I'd just come home from a long, seaside dinner with a close friend. I was hours away from INOVA's pulmonary and critical care center in Northern Virginia where my brother Bruce's lung transplant surgery would take place, and I felt an adrenalin rush overtake my wine buzz.

I knew this call would come, but I hadn't expected it so soon, and I thought I'd feel more prepared than I was. Should I get in the car now, or skip the wheels and look for a flight? I paced and looked around the room as if I were searching for missing keys. During those few blurry minutes after you get news like this, you want to march into a war room and see a focused team manning their battle stations. I saw nothing but treetops and a half moon when I looked out the window. I went downstairs to make coffee and settle in for an unsettled night.

My earliest memories of Bruce are of his patience as we fished for God knows what kind of catch in Bull Run Creek behind our house in Centreville, Virginia. I was five, so it took a long time to inch me down the path from our house to the water. I fidgeted after only a few minutes, despite my promise to sit quietly and let my brother lose himself in the timeless Zen of baiting and waiting.

He would return me to the house when I wouldn't let him be, but I don't recall him losing his patience, even though he was only a kid himself. He told me recently that it was the quiet, not the fish, he craved.

Later, when I was six and Bruce was thirteen, he had to talk me out of spoiling Christmas for our parents. I had discovered their secret hiding place for presents behind the washing machine.

"Look what I found," I squealed. He looked concerned and sat me down.

"Let's just keep this our secret, OK?," he said. "Mom and Dad really get a kick out of surprising you, and you don't want to ruin that for them, do you?"

I did, in fact. My mischievous expression led to an offer.

“I’ll tell you the deal if you don’t let on to Mom and Dad, OK?”

I agreed and discovered that Dad was Santa Claus who set up the train set, and Mom was his lookout in charge of keeping the kids upstairs. I felt connected, sharing my first “grown-up” secret with my brother.

Now Bruce is 63, and he lives just a few miles from our childhood home in a suburban metropolis that was once a one-horse town. Instead of casting rods onto the moving water and spending days unconcerned with the passage of time, we keep our eyes on life’s ticking clock.

Bruce has [Idiopathic Pulmonary Fibrosis](#), a disease that occurs when lung tissue becomes damaged and scarred and makes it hard to breathe. His early symptoms were a troubling cough and shortness of breath. Bruce is the type of guy who would never want to trouble you with anything. He’s more interested in how you’re doing, as the doctors and nurses tending to his care learned during his visits, when he’d bring his medical team treats and shoot the breeze while they made their assessments.

No one wanted to say it, but we all knew it: Bruce’s illness was progressive and could kill him quicker than he or any of his loved ones were prepared for, unless he got treated immediately through his Affordable Care Act healthcare plan.

My brother has been living with just one kidney since a few months after he was born; this is considered a preexisting condition. Based on the [list of what the GOP has considered preexisting](#), from acne to pregnancy, who among us doesn’t have a preexisting condition? Like millions of Americans, he doesn’t have health insurance through an employer. He’s worked as an independent contractor off and on for years. He did have coverage through an employer recently, but when the small business owner discovered Bruce faced costly health issues, he was laid off. The ACA has been his only healthcare option since.

In fall 2016, his symptoms worsened—he was wheezing and tethered to a portable oxygen tank. I recall feeling worried but impressed by how casually he inhaled through his mask. Despite his focus on staying healthy and doing all he could to maintain his lung health level, Bruce’s doctors determined that he needed a lung transplant. His name went on a list, which meant he

kept his phone on 24/7 with the knowledge that, at any moment, he might get a call and need to go to the hospital immediately.

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[CNN reported](#) that “The healthcare industry has made huge scientific advances in the past 50 years, but all that work has come at a very literal cost. In 1967, Americans spent \$43.5 billion on healthcare expenses. In 2016, we spent \$3.4 trillion, which adds up to about \$10,350 per person. That’s a whole lot more of an increase than inflation alone can explain—and far more than most people can afford.”

There are so many variables that go into why universal healthcare isn’t an American reality: Citizens who don’t see it as a right; the greed of drug companies and corporations who are profiting off the lack of regulations in what should be a system that is regulated in the name of the public good; the apathy and profit motives of politicians in the pockets of the drug and healthcare lobbies. But out-of-whack costs have made it crucial.

I think of healthcare in retail terms. Can you think of a product you buy regularly that has more than a four-time markup? Wholesalers buy a bottle of wine for \$3.99; you purchase it at the liquor store for \$15.99. More or less, it’s the same with food, household goods, clothes...you name it.

But with healthcare, if I have a bout of diverticulitis, and I’m admitted to the hospital for an overnight stay, with a few tests thrown in for good measure and two terrible meals, I may end up with an invoice for \$6,000, which is what happened to a friend of mine. I am tired of hearing arguments of how much Pfizer spends on research and development. Even factoring in some margin for R&D, the costs are not only nontransparent, but to paraphrase Mr. Spock, they are highly illogical.

It’s an exponential markup that’s led our country to an existential crisis.

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Late-night talk show host Jimmy Kimmel became my late-night hero after breaking down during a recent monologue as he described his terrifying experience with his [newborn son’s heart condition](#). On the heels of House Republicans passing a bill to roll back coverage for millions of Americans,

Kimmel revisited health care and a possible ACA repeal on his show, defining what he described as “the Jimmy Kimmel test.”

Under the Jimmy Kimmel test, “no family should be denied medical care, emergency or otherwise, because they can’t afford it,” he declared.

I choked up and cheered from my sofa that night and continue to do so as Jimmy sticks to the cause, relentlessly calling politicians on their lies and inhumanity. I needed to hear a public figure with a big audience hit the kind of powerful note Jimmy hit – one that I hope will resonate with Americans.

Kimmel’s principled stand before the public reflects and magnifies the millions of small, scared, and often devastating conversations Americans are having about their health right now. Like the one I had with Bruce in the summer of 2016:

“Listen, I have something to tell you,” he said, in an uncharacteristically dramatic moment during a car ride to see our mom. “I’ve got an issue with my lungs, but the good news is I have great doctors.”

It’s so like him to downplay, I thought. My antennae went up that day, and they’ve stayed up ever since. For more than a year, I’ve been on a heightened state of alert, which I know Bruce will hate hearing. He’s always been one to deflect family worry, despite times when I thought it was warranted. Like the times when he didn’t have any healthcare coverage. The day he got his ACA coverage, I breathed a huge sigh of relief. He’s had an excellent experience in that program, with helpful doctors and reasonable premiums.

Since his diagnosis, I’ve written dozens of letters and made calls to my representatives and House and Senate leadership, urging them to focus on sensible fixes in lieu of a childish ACA repeal that seems motivated only by hatred of Obama and by Trump’s need to have his gilded name on everything from buildings to bills.

I skip fact-check-free talking heads and dive into details about potential healthcare changes from trusted sources like *The New York Times* and *The Washington Post*, so I can stay informed, active, and ready to resist.

I follow all sides of the debate, but once you drop from the blurry 30,000-foot heights of hypothetical plans and pie-in-sky projections to the ground, the healthcare fights faced by families like mine come into clear focus.

Two weeks before Bruce's call about the transplant came, and right after the House's May 4 vote to repeal the ACA, I posted the following on Facebook in reaction to that vote and to one of many callous statements from GOP leaders:

Only people with "good lives" deserve healthcare? If you have a preexisting condition, "you should move" to another state? What sad, miserable people you must be to think and say things like this.

What happened here today is that passing bullshit was more politically advantageous than admitting you have been wrong all along. Fixing Obamacare is the obvious solution that the majority of Americans prefer.

My brother has a very serious health condition, as a lot of you know. His doctors and the medical people he's working with are heroes—they can't stand what's happening in Trump/Ryanland.

No family should ever have to risk bankruptcy to handle an illness. It's not right, not in the greatest country on earth. You want to argue that? Please unfriend me because I'm tired of explaining decency.

2018 elections can't come soon enough. Remember who voted and how. Stay involved and resolved.

While Trump celebrated with GOP leaders in the Rose Garden, all I could think was *misery may love company, but insanity seems to need it.*

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I recall what Kurt Eichenwald, a *Newsweek* staffer who suffers from epilepsy, tweeted during the healthcare bill coverage debate: "As one w/preexisting condition: I hope every GOPer who voted 4 Trumpcare sees a family member get long term condition, lose & die."

He's since deleted the comment, and many reacted to his words with horror. But the House passing the repeal of the ACA felt like a knife in the heart to me, and I understood his outrage. How can Congress expect people who face

– or whose loved ones face – life-threatening illnesses to react with serenity?

“Oh, it’ll never pass the Senate, so who cares?” a friend of mine had said back then, in a moment of colossally bad timing.

“Being blasé is just an excuse for not caring,” I replied. “Based on what’s been happening in Washington, nothing once unthinkable seems off the table anymore.”

I was proud of Bruce for calling his Congressman’s office to express his concern.

“I told them that if the repeal went through, I would, in effect, be the walking dead, which I did not mean as a reference to the TV show,” Bruce said. “I could’ve said dead man walking, but that’s a little too green mile and distracts from the issue. The guy on the phone said he wrote down my name and address, and he almost seemed concerned for three and a half seconds.”

Genuine concern came from Bruce’s medical team.

“You have no idea what’s coming,” his doctor told him. An ominous statement from someone on the front lines of helping people, who’s seen—and more importantly, will continue to see—patients in need of urgent and life-saving care instead receiving the silent treatment from politicians who don’t want to hear about their terrible choice: potential bankruptcy due to healthcare costs or forgoing care and facing death.

I am convinced that the healthcare professionals who helped my brother this past year and ushered him into surgery this past spring did so with lightning speed and heightened urgency, not just because of lungs that would fail him, but because of a health system that would fail him even sooner.

I’ve seen the lengths to which Bruce’s doctors are going to care for patients like him, patients they know risk being hurled under the healthcare bus. To me, these doctors and nurses are the saviors of our time, shepherding people like Bruce through the system while they still can, before the Ayn Randian world vision of Paul Ryan, Mitch McConnell, their GOP cronies, and the current sociopath-in-chief can be fully implemented.

Bruce's team also urged his family to establish an online fundraising website on the HelpHOPELive platform—a GoFundMe.com for healthcare. The doctors told us the costs associated with transplants can be astronomical. Even with insurance covering the surgery and hospitalization, there are out of pocket co-pays and deductibles, medications, doctor visits, and important therapies and treatments that are necessary to keep him thriving for years to come.

We followed their advice and reluctantly created a [website](#) for Bruce last February.

"I don't want to see it," Bruce said.

I don't blame him.

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Of all the songs to hear during the excruciating waiting hours while Bruce underwent his lung transplant, *He Ain't Heavy, He's My Brother* was the one I dreaded most as I listened to my favorite radio station and waited for news. For some reason, Ocean 104.7 kept the Hollies song and *Use Me* by Bill Withers on regular rotation. I knew the lyrics by heart, and they'd been on my mind since Bruce's diagnosis.

And there it was: [The Hollies](#) singing their big 1969 hit while I drove to the Stop & Shop to pick up groceries and maintain normalcy during a weekend devoid of both, and Bruce transitioned from the long surgery into recovery and then to the ICU. I moved to change the channel, but stopped and let the song play. I indulged in two minutes of stillness and sappy fear before taking a deep breath and driving on.

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My brother's fight for survival ignited a fire in me: Fury at callous politicians, like the ones who claim healthcare is only for those who lead "good lives" and suggest it's just tough luck for anyone denied coverage based on a preexisting condition. A mission to repeal and replace politicians who value ego over progress, profits over people, and selfishness over decency.

I've been waiting to finish writing this essay since last June, thinking we'd finally land on terra firma with healthcare in this country, and I'd have the end of the story. But we haven't. The fight against what the GOP love to sneer

and sniff at dismissively as “Obamacare”—they are usually shaking their heads when they utter it—is like a *Friday the 13th* movie. In the latest Senate fights, it’s been Mitch McConnell as Jason Voorhees sans creepy catcher’s mask, returning from the proverbial dead to attack yet again. John McCain is cast as the film series’ hero, which seems fitting since he is an authentic one.

So a news lede for this essay doesn’t stick. Nor does Bruce’s health status remain static; no one’s does. What does attach like Gorilla Glue is the GOP’s endless fight to repeal the ACA. “Repeal” is now a misnomer. Dismantle bit-by-bit is the correct description at this point: Start by taking away coverage options for our poorest, while striving for tax cuts for the rich. Actually, the word “crush”—out of a desire to see that Obama’s name isn’t left on anything vital—feels more accurate.

On October 12, Trump [signed an executive order](#) to end subsidies for low-income people, while putting in place cheaper policies that reduce benefits and consumer protections. “With these actions,” Trump said, “We are moving toward lower costs and more options in the health care market, and taking crucial steps toward saving the American people from the nightmare of Obamacare.”

How will we save ourselves us from the nightmare of Trump?

Imagine you’re at the opening of a play and you need to write a review of it during intermission. You have the gist, you see where it’s going, but you don’t know the ending.

“Plays are never finished,” my playwright friend Marthe told me recently. I am starting to think the fight for universal healthcare is a play, and we are in perpetual intermission. I have to stop and print my review now, but I don’t know the ending, and I have the vague, unsettled feeling that it will never be over.

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Amy told me that after the “little surgery grandpa had,” her soccer-loving seven-year-old’s first question was, “Will grandpa be faster?”

Overall, Bruce’s prognosis is good. He’s breathing better. Following his post-surgery recovery, he developed a bacterial infection that required weeks of

powerful antibiotics to tame it. But he bounced back, and during a two-mile walk with Amy, her son, and my new puppy, Bruce walked faster than me. I drove away elated.

It's easy to be lulled into thinking he's back to normal. Five days after our walk, he came down with pneumonia that overtook him before he knew what had happened. His fever, congestion, and cough put him in the critical care unit. We've learned how common the sudden onset of a serious threat is for those on immunosuppressive drugs.

Bruce and I have been in frequent touch since his surgery. In one text exchange during the many ups and downs of healthcare bills, he wrote:

"...it is perfectly legitimate to describe my health care situation as tenuous, if not perilous, not to overdramatize. I am able to walk around with my new backpack set-up and would be glad to join you at any local marches or gatherings. I think seeing somebody needing oxygen has more of a visceral impact than just talking about it. One of the big takeaways...is never stop fighting, never become complacent and take freedom for granted – fighting for rights needs to be a lifestyle and a lifetime commitment."

For the foreseeable future, he'll continue on a rigid regimen that seems like a full-time job: exercise, medications, therapy visits, checkups, and treatments.

I wrote notes after the surgery, thanking doctors, friends, and family, and paying tribute to Bruce's lung donor. "I feel eternal gratitude," I said. I didn't share that I also feel eternal concern.

If Bruce fears more lung trouble down the road, or loss of the healthcare coverage that saved him once and might need to again, he doesn't share that with me. He's loaded with purpose and a positive attitude. But I know we're both furious at the uncaring leaders who don't see anyone's face when they plot and plan the destruction of a healthcare system that, while not perfect, had moved us closer than ever before to taking care of Americans who need it.

I consider the specter, and I know my entire family does, too. The thing about healthcare that politicians don't seem to get is that there is no such thing as individual coverage. Coverage is also for the family who will be devastated if

a loved one leaves us, especially for an immoral reason like healthcare costing so damn much.

Sometimes when I stop and think about the future, I'm still in the car that Saturday in May, driving to get groceries and lost in the temporary illusion of normalcy, listening to the Hollies.

The road is long.

