
FIELD NOTES | FALL 2020

So Sorry to Bother You, But I Might Die If You Don't Wear a Mask

By Katherine Macfarlane

I'm an immunocompromised person living in Boise, Idaho, a COVID-19 hotspot where no one wants to wear a mask.

"I need you to wear a mask," is what I say instead of "hello" when I meet someone new.

No one replies with an apology. Instead, they argue.

The UPS delivery guy who rings my doorbell doesn't want to wear a mask while standing less than six feet away from me because, "I just need you to sign for this package real quick."

The woman in the locker room at the gym doesn't want to wear a mask.

"I can't wear a mask when I shower!" she tells me, aghast, like I'm crazy for suggesting that she mask up. She is no longer in the shower when we have this conversation.

Here in Boise, people don't just refuse to wear masks, they gather at anti-mask protests in front of City Hall and burn them.

One protestor explained that the burning of masks was symbolic, "just like when they burned the bras."

Except no one burned bras. In 1968, women protesting the Miss America pageant tossed bras into a trash can.

The ignorance would be funny if it weren't also violent.

This summer, the Idaho legislature convened at the Capitol in downtown Boise for a special session about the pandemic. Protestors shattered a glass door on the Capitol's fourth floor.

They filled the public gallery and did not socially distance.

The Capitol is across the street from my office.

So, I lay low. Since June, I've only left my home for two reasons: medical appointments, and trips to the YMCA, where I swim in the therapy pool.

The YMCA has great protocols in place. You have to reserve a lane if you want to swim, and there's only one person allowed in each lane at a time. Each reservation is for a 45-minute slot. Pull buoys and kickboards are sanitized after each use.

I have Rheumatoid Arthritis (RA). Lap swimming, which really helps my joints, is relatively safe. It's an activity that's unlikely to result in COVID transmission.

But protocols mean nothing without enforcement. The YMCA requires its members to wear masks in the locker room. On a good day, half of the women in the locker room comply. "What do you do when someone doesn't wear a mask?" I ask the YMCA employee folding towels at the check-in desk.

"You can't really do anything," she tells me.

I get scared and cross the YMCA off my safe list. My world gets smaller and smaller.

Not even my medical appointments are safe. During an eye exam in which my doctor's face is less than a foot from mine, his mask falls below his nose. Instead of pulling it back up, he pulls it down to his neck.

"Doctor, I know it's uncomfortable, but I need you to put your mask back on," I say.

"Oh. I thought you couldn't hear me," was my doctor's explanation.

I never said I couldn't hear him.

The doctor is an ophthalmologist. Most of his patients are at least 80 years old. His waiting room is packed with the city's most high-risk, vulnerable folks. Doesn't matter. No one cares. I'm half the age of the average patient, but I have old people problems.

I was diagnosed with RA when I was 13 months old. I also have uveitis, a form of inflammatory eye disease common in patients who are diagnosed with RA as children. Uveitis is treated with topical steroids, which can cause cataracts and glaucoma. I had my first cataract surgery at 23, the month before I started law school. I had my second cataract surgery at 27. I had my first glaucoma surgery at 31, my second at 32, and my third at 38. Still, I've lost half of my vision in my left eye. Right now, there is uncontrolled inflammation in both of my eyes, and my intraocular pressure is spiking, which could lead to more vision loss. There is eye surgery in my future.

My RA is also out of control. RA is an autoimmune disease that causes joint deterioration and pain. It's treated with immunosuppressants. I take three. This means that I take three medications that would independently make me high-risk for serious illness from COVID. All together, they pack a mean immunosuppressant punch.

Under normal circumstances, I'd treat my flare with a steroid pack. But steroids are immunosuppressants, and I can't be any more immunocompromised right now. Swimming would really help, but the carelessness of others renders the pool too dangerous.

I'm overwhelmed by pain and loneliness. It's obvious that "we" are not in "this" together. My isolation will persist as long as the recklessness of others continues. It shows no signs of stopping.

Some folks are trying their best. My rheumatologist has COVID protections down cold. She makes her patients wash their hands, while her nurse watches, before they enter an exam room. You have to hang your purse on the back of the exam room door—it can't touch anything else.

At the ophthalmologist's office, his receptionists answer calls with their masks pulled down to their necks.

At the eye doctor's office, the techs pull down their masks in between appointments, and huddle in small exam rooms in groups of three or four. I hear them planning a weekend outing to a local restaurant that serves patrons indoors.

When I'm in an exam room at the eye doctor's office, I ask that the door remain open. It's a small, indoor space with little ventilation.

"We can't do that," one of the techs tells me, "because of HIPAA."

Whenever someone says "HIPAA," I want to scream. Inside my heart, of course. HIPAA is a law meant to protect against the disclosure of confidential patient data. But HIPAA is often invoked by healthcare professionals to justify every misinformed office protocol. Nine times out of ten, when someone says HIPAA, HIPAA has no application. So why does HIPAA require that my exam room door remain closed in the middle of a pandemic caused by an airborne virus? Under normal circumstances, examinations should be conducted behind closed doors so that information regarding a patient's health isn't heard by others in the waiting room. I suppose that HIPAA compels this outcome, but so does common sense. Still, patients get to decide when they want privacy protections, HIPAA-based or otherwise, to be waived. HIPAA does not bar a patient from choosing to diminish her chances of contracting a deadly virus by asking that an exam room door remain open. My request has annoyed the tech. She has yet to measure my intraocular pressure, and I'm worried she's going to be rough. I watch her sanitize her hands, and then touch a drawer handle and a pen.

She reaches one hand toward my face to pull down my eyelid to administer numbing drops, and I dodge.

"I know you just used sanitizer, but you touched a few other surfaces and I'm on three immunosuppressants, I just have to be extra careful," I explain. Moments earlier, we reviewed my medication list. She knows how sick I am.

"I need you to sanitize your hands again," I say, as politely as possible.

The tech rolls her eyes and re-sanitizes her hands in slow, exaggerated movements.

“Thank you so much, I’m probably just being paranoid!”

Silly me, trying to stay alive.

I ask the two receptionists out front to put their masks on before I approach their desks to check out. Again, I explain that I’m “severely immunocompromised.”

I need better words.

Only one receptionist complies. She gives me the stink eye when I approach to schedule my follow-up appointment.

My eyes are in such bad shape that I have to see the doctor twice a week. I am limping and moving very slowly because my knees are swollen and bent. Each step is painful. Outside the doctor’s office, a kind stranger asks me if I need help getting to my car. Inside my own doctor’s office, no one cares.

I’m sure they’ll call me a bitch after I leave.

This bitch just isn’t ready to die.

Katherine Macfarlane writes about chronic illness and navigating the U.S. healthcare system. Her essay “Flying Into Jerusalem,” about finding out that having Rheumatoid Arthritis would keep her from having children, was anthologized in *Bodies of Truth: Personal Narratives on Illness, Disability, and Medicine*. Her essays have appeared in *BUST*, *Ms.*, *Hairpin*, *Huffington Post*, *xojane*, *Northwestern Magazine*, *Foliage Oak*, *Tenemos* and *NolaVie*. When she’s not writing about harrowing healthcare experiences, she teaches Civil Procedure and Civil Rights Litigation at the University of Idaho College of Law. Katherine received her B.A. from Northwestern University and her J.D. from Loyola Law School, Los Angeles. She was born in Toronto, and grew up shuffling between Kalamazoo, Michigan and Rome, Italy. Katherine lives in Boise with her dog Cooper. Follow her @KatAMacfarlane. Her Field Notes essay “So Sorry to Bother You, But I Might Die If You Don’t Wear a Mask” appears in the Fall 2020 *Intima*.

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