

**GLOBAL FEMINISMS
COMPARATIVE CASE STUDIES OF
WOMEN'S AND GENDER ACTIVISM
AND SCHOLARSHIP**

SITE: UNITED STATES

**Transcript of Chimère Smith
Interviewer: Abigail Dumes**

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Suffering with the debilitating effects and symptoms of Covid-19 for nearly a year, **Chimère L. Smith** has had to learn the hard knocks of advocacy in healthcare. While seeking treatment and care, she experienced racism, sexism, and dismissal by several medical professionals. Chimère boldly took matters into her own hands by challenging Baltimore hospitals for better, comprehensive treatment for herself and other Black Long Covid patients in urban communities. She is an author, speaker, highly-requested panelist, and thought leader who unapologetically shares her Long Covid journey — including balancing the effects of her disability emotionally, physically, and financially. Chimère Smith has been featured on CBS, CNN, MSNBC, NPR, PBS, and in *The Washington Post*, and *The New York Times*. She has written for *Huffington Post*, *Medium*, *The Long Covid Survival Guide*, and *She Knows*.

Abigail Dumes is a medical and cultural anthropologist and an assistant professor in the Department of Women's and Gender Studies at the University of Michigan. Dumes received her PhD in sociocultural anthropology from Yale University, and her first book, *Divided Bodies: Lyme Disease, Contested Illness, and Evidence-Based Medicine*, was published by Duke University Press (2020). Her ongoing research explores the relationship among gender, contested illness, infectious disease, and environmental risk in the United States; she is working on a new project on Long COVID.

Abigail Dumes: Hi, my name is Abby Dumes. My pronouns are she/her. I am a white woman with a red floral top. I have circular gold and silver earrings, and I have brown hair and a braid over my left shoulder. In the background, there is a red framed painting, and to my right are bookshelves. Chimère L. Smith, thank you so much for being here, and being willing to share your story with the Global Feminisms Project. I'm going to briefly introduce you, and then we'll move on to our questions and also let you introduce yourself.

Chimère Smith: All right, thank you so much.

AD: Chimère L. Smith, is a Baltimore-based Long COVID¹ advocate, consultant, and educator. She is a former middle school teacher, and in 2019 was selected as a Stanford University Hollyhock Teaching Fellow.² Since June 2020, she has raised awareness about the importance of Black voices in conversations about, and organizations related to, Long COVID prevention, treatment and research. Chimère was a board member of Body Politic,³ a quote, "Global network of COVID-19⁴ patients, chronic illness allies, and health and disability advocates." And, has recently been appointed as a volunteer consultant for #ME Action,⁵ where she is seeking to engage a more racially diverse volunteer network.

CS: Should I just—will I just let you—

AD: Yeah, of course.

CS: Thank you so much, Abby, for having me. I appreciate that. I am Chimère Smith. I am a Black woman with a black tank top on. My hair cut is very, very low and short. My earrings are gold with navy blue and white stripes, The couch behind me, which I call, "Chimmy's

¹ Long COVID refers to the long-term symptoms that an individual may experience after an initial COVID-19 infection. ("Long COVID or Post-COVID Conditions." Centers for Disease Control and Prevention. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html>. Accessed 13 January 2023.)

² The Stanford University Hollyhock teaching fellowship helps young high school teachers to further develop their skills to make a difference in their school's communities. ("CSET Professional Learning." Center to Support Excellence in Teaching. <https://cset.stanford.edu/pd/hollyhock>. Accessed 13 January 2023.)

³ Body Politic is a feminist organization based on inclusion that provides awareness on issues concerning health and politics. ("Who We Are." Body Politic. <https://www.wearebodypolitic.com/>. Accessed 13 January 2023.)

⁴ COVID-19 is a respiratory illness that is highly infectious. This disease is particularly dangerous as it is possible for anyone to become seriously ill. ("Coronavirus disease (COVID-19)." World Health Organization. https://www.who.int/health-topics/coronavirus#tab=tab_1. Accessed 13 January 2023.)

⁵ #ME Action is an organization that is dedicated to bringing awareness and more research to ME, also known as Myalgic Encephalomyelitis. ("Our Mission." #MEAction. <https://www.meaction.net/about/>. Accessed 13 January 2023.)

couch," is a dark teal color, and the pillow to my right—I'm sorry—Yeah, to my right, is purple, light blue, teal, white, and cream.

AD: Thank you so much.

CS: Thank you.

AD: So, we're just going to jump into it. We're going to start with you thinking about where you are today. And thinking about where your story begins, and helping us connect the dots between where your story begins, and the journey that brought you to this point.

CS: Yeah. Absolutely. Today, as I talk to you, it has been—I feel a little bit vindicated, you know? I'm glad that we're talking today, because, as of today—I am now fully being recognized as a Long COVID patient: by my doctors, by other medical care professionals. And I am excited to say that. But even as I think about that, I get emotional. Because, that happened yesterday, where I was formally recognized. But it has taken *two years*, you know, it's been *two years* since I became sick with Long COVID.

AD: Wow.

CS: My story started in March of 2020. I was at that time—before I got sick—I was a what I will call, a *baaaad* teacher. And when I say "bad"—I don't mean "bad," in the sense of horrible. I mean I was like *Michael Jackson bad*.⁶ I was on point. I was very invested and engaged in my students. I taught for Baltimore⁷ city public schools for five years. I taught at a mostly urban—you know, in an urban area with Black and Latino students. And I was proud to be a teacher. And, you know—what was so ironic—Is that: the week before we were scheduled to come out of the classroom because of the pandemic. We were sitting in a circle having a listening session: teacher and students. And the students were expressing their concerns about COVID. Because they had been reading the news; seeing the news; hearing their families, who were working in medical environments. And they were—they were scared. They were concerned. And as a teacher, it was my job to, you know, assure them that they were going to be okay. But *none* of us truly knew about the impact that

⁶ The term 'Michael Jackson Bad' means something that in actuality is good, but is referred to as bad to have the connotation of being cool. ("Michael Jackson bad." Urban Dictionary. <https://www.urbandictionary.com/define.php?term=michael%20jackson%20bad>. Accessed 13 January 2023.)

⁷ Baltimore is a highly populated city in Maryland. It is known for the many rich histories that occupy the neighborhoods. ("Baltimore." Wikipedia. <https://en.wikipedia.org/wiki/Baltimore>. Accessed 13 January 2023.)

COVID would have. And I certainly didn't know what I was going to be in store for less than two weeks later.

AD: Wow.

CS: And so, you know—We were told by the Governor of Maryland⁸ to stay home and to protect ourselves, and I did that. At the time I was living with a romantic partner. And we had gone and—you know—bought us, you know—bought as much supplies as we could: water, hand sanitizer, napkins, tissues, you know—everything that we thought that we would need, including food. And about a week later, while I was talking to my therapist my—I started to feel a tickle in my throat. And I—And I noticed it, and I was just like, “Okay, maybe it might be allergies, you know—this is around the time, March, where I would get seasonal allergies and I would suffer a bit.” So, I tried to kind of shake that off, and say, “Okay, I’ll—you know—I’ll take care of it. I’ll take an allergy pill later after my appointment with my therapist.” And—what started off as a scratchy throat turned into what I—what I consider to be the most monstrous fatigue I’ve *ever* felt. I’ve *never* been so tired. It felt like it was like 10 weighted blankets on me. My head started to feel unclear. I started to feel very unclear, like the way that you feel when you have a horrible cold or the flu.⁹ I—when I would stand up, I would feel extremely tired. My heart would race so fast I couldn’t—I almost had to hurry up and sit back down. I was trying to—I remember the day I was trying to do a dance. [chuckles] Because I was trying to make myself feel better. And I couldn’t do the dance, you know, for more than two minutes, because I was so sick, and I felt so heavy at that time. I had diarrhea. And I thought it was because, you know, just thinking like, “Oh, I just have a little cold or something something”—you know. And I started to get migraines and headaches. But there was one day that I woke up—actually the next day. I woke up, and I was trying to stretch my body. And in the midst of stretching my body, my back: I had the worst burning searing pain in my spine. And I thought to myself, I said, “something is not right with me. I don’t feel well. There’s something going on,” and so I decided to—I called a couple of friends, my best friend being one of those people, and I said—I was like, “Girl, do you think I have COVID?” And she said, “You know,” she said, “Well, I hope not,” she said. “But it just sounds like you just might have a little cold,” she said. “But—you know, if you need to—try to get a test, and you know, take care of yourself.” And I said, “Okay.” ‘Cause everybody I knew was on lockdown. So, we weren’t seeing each other except for Facetime or Facebook messenger. And so, I decided that Tuesday night, after being—not feeling well for the past three days—That I would—I would get into my car

⁸ Maryland is a state located in the eastern United States. It is bordered by the Atlantic Ocean on the east. (“Maryland.” Wikipedia. <https://en.wikipedia.org/wiki/Maryland>. Accessed 13 January 2023.)

⁹ The Flu, or Influenza, is a contagious respiratory illness that can be identified by symptoms including fever, cough, fatigue, and more. (“Flu Symptoms & Complications.” Centers for Disease Control and Prevention. <https://www.cdc.gov/flu/symptoms/symptoms.htm>. Accessed 13 January 2023.)

Wednesday morning, and I will go home. Home, you know, for me, at that time was with my—I was living with my god—my godmother. And I left my partner's house, and I said, "Because if I—If I was sick I didn't want to get him sick." And um—There were some discord between us, because I started to feel like I had COVID. I just had no—had no real knowledge at that point. I was just like, "Something about how I feel, doesn't feel like anything I've ever experienced or felt in my life." And so, the next day I left his house. But, you know—I went to the doctor. The doctor, the first doctor, was my primary care physician at that time, who said, "Oh, you're fine. You just have a sinus infection."¹⁰ Take this Flonase.¹¹ Take these antibiotics, and you'll be fine." And I went to another physician and was told the same thing. But I also was told that, "if you do have COVID—there's no way we can test you, because you look fine. You're not short of breath. You're not coughing. You don't have a fever. So, go home and rest, and you'll be fine." When I went home Wednesday, I decided that night to go to the hospital because I felt horrible. I wasn't getting any better. Nothing was helping. And I went to the hospital around the corner from my house, and—It was zombie land in the hospital. Because only people who were really sick were allowed to be there. And once again: I was told that I could not be tested, and I was giving them, by that time, I had a list of symptoms. And I was providing lists of symptoms. And I was told, "Go home. You'll be fine. If you have COVID—you'll be fine in two weeks." And that happened to me going to the hospital subsequently like that for—I went to the hospital total of like 12 times. I went between two hospitals. And each and every time I was told the same thing. I was being thrown medication, but nobody would test me the first few times I went. I did not get a COVID test until two weeks after my illness, the onset of my illness. And what I started to notice when I went to a local hospital in Baltimore, one of the best and the brightest in the country, is that—I would be I would be sent to rooms to sit for hours and hours and hours and hours. And I would hear—um—I would hear people talk about men, and they would say, "Oh, Mr. Such and Such has a suspected case of COVID so we're going to treat him with this." And I would look over across, because I was—you know—In rooms where I could see a little bit across from me. And I would see these were white men, these were Asian men, these were men. And I kept wondering, I was like, "Why are they getting treated before me? Why are they saying that they have a suspected case of COVID? Here I am coming with a myriad of symptoms and nobody's addressing why—as a 37-year-old, healthy woman. I have—at that time, I became constipated; I wasn't pooping. Frequent urination, heart palpitations, loss of smell, loss of taste, dizzy, confused. As time went on, at the end of April, I lost my vision in my left eye. Nobody seemed to care about

¹⁰ A sinus infection, or Sinusitis, is caused by the buildup of fluid in the sinuses. Symptoms of a sinus infection include a runny or stuffy nose, sore throat, or pressure in the face. ("Sinus Infection (Sinusitis)." Centers for Disease Control and Prevention. <https://www.cdc.gov/antibiotic-use/sinus-infection.html>. Accessed 13 January 2023.)

¹¹ Flonase, or Fluticasone, is used to help alleviate symptoms in the nose such as a stuffy or runny nose and itchiness in the nose. ("Flonase Spray, Suspension – Uses, Side Effects, and More." WebMD. <https://www.webmd.com/drugs/2/drug-1474/flonase-nasal/details>. Accessed 13 January 2023.)

me, you know? And what was happening to me. Menstrual periods were so heavy and so irregular which, you know, I know my body, so I was just like—

AD: Right.

CS: “—Hey, something is wrong here.”

AD: Right.

CS: And so I started to—I was going to the hospitals. There was nothing happening. They were dismissing me. I was driving myself—even though I couldn't really see—trying to get answers. Begging hospital staff to let me stay for them to examine me. Nobody would help at all. Just would send me home, it would be the middle of the night and they'd say, “Oh, there's nothing wrong.” Then they started to—to suggest—that there was something psychologically wrong with me.

AD: Was that explicit? Were those suggestions—?

CS: Yeah [nods head up and down]. Absolutely.

AD: Yeah.

CS: I was invited to stay in a behavioral section of a hospital. Like, “Oh, you've been here all these many times, and nothing is wrong with you. Maybe it's something that's—you know—maybe you need some mental health help.” And I was like, “No, I'm getting mental health help. I go to a therapist every week. I want you to tell me what's wrong with me.”

AD: Right.

CS: “I was healthy before this: what's wrong?”

AD: Right.

CS: So, the more I started to see that. Feel that. And I started to feel in such despair. And I thought—truly, that I was going to die, Abby. I was—I—by the time we got to May: I was planning my funeral. I was—I had sent a will to my best friend. I had told her, “Here is what we're going to do, if I don't make it out of this hospital tonight, or if I don't make it home, or you call”—she has now—she has all my—all the important phone numbers. Every number that's important to me. She knows how much, you know—bills I have, responsibilities, who to give what to—because I assured her in May, that this is what needed to happen and

um— [long pause]. By the time June happened, or June came of 2020 I had gotten tired of being—I had gotten sent home that one last time before I started to take action. And I said, “I am sick of this shit.” Okay, excuse me, and you know. Yeah—

AD: No—of course.

CS: And I say, “I am tired of this.” And I called my best friend, who has been the most incredible woman, Sequoia Thompson,¹² to me. And I said to her, I said, “if I’m going to die from this—from COVID—because I knew I had it— I said, “if I’m going to die from COVID: I am going to go out with guns blazing.” And what that meant for me was: I was going to talk to anybody who would listen about my circumstances. I was tired. Not only was I fueled by just being a Black woman that was tired. I was also fueled, because I started to—I joined the group, Body Politic. And I was reading stories from people all across the globe, who were dealing with the same treatment. And I was fueled by the fact that all of us were being mistreated. But then I started to think: I said, “you know—the group was—is—mostly, you know, comprised of white people. And I said, “While I feel for them; I feel for all of us. I especially feel for me, because I’m a Black woman living in an urban community, what I call, ‘the hood.’”¹³ I teach in the hood. I grew up in the hood. And if I’m going to these hospitals and experiencing this this way. My babies, who, by that time in June, I had not—my babies, my students—I don’t have any children—but my students, who I had not seen by that time in three months. If *they* were experiencing this: they would go to the hospitals and they wouldn’t necessarily know how to communicate or articulate these experiences, and they would be treated the same way. And so, as I thought about us. ‘Cause initially it was selfish. Advocacy usually starts off with—from selfishness. Because we’re trying to find a way to disrupt systems for ourselves first. Or for somebody that we love or care about. And then we start to think about: how what’s happening to us impacts other people. And so I thought about my students. Those students who live in nuclear family¹⁴ homes. Students who didn’t have enough health insurance to get vaccinated. Students who didn’t even usually—on most days—have money to buy—to get lunch, or to get additional snacks. I thought about: If they had to make it to the hospital, what would happen to them? And so—In a dark, dark room where I spent about a year of my life. It ended up being a year in a dark room. I started to—I picked up my phone: I picked it up. And I said, “with this one good eye: I am going to email every Baltimore City Council person. Every Maryland state delegate that I can find.” [short pause] And I did that. I did that. And it took about—Not even a day, where

¹² Chimere Smith’s best friend.

¹³ “The hood” refers to a neighborhood with that is mostly occupied by individuals of low socioeconomic status. (“hood.” Dictionary.com. <https://www.dictionary.com/browse/hood>. Accessed 24 January 2023.)

¹⁴ A nuclear family is a type of family that consists of parents and children that usually live in one home all together. (“Nuclear family.” Wikipedia. https://en.wikipedia.org/wiki/Nuclear_family. Accessed 13 January 2023.)

my City Council Member, Kristerfer Burnett,¹⁵ who I will never, ever forget. He reached out to me and said, “I am going to do some investigating with Johns Hopkins¹⁶ and St. Agnes Hospital¹⁷ in Baltimore, and we are going to get to the root of this problem.” And so—

AD: Was that the first response that—?

CS: Yeah. It was the first response.

AD: It was.

CS: Then I heard from—you know—Nick Mosby,¹⁸ you know—who was at that time, a State Delegate. Mary Pat Clarke,¹⁹ who was at that time—she's retired—a City Council Woman. People were—were speaking to me, and they were expressing their sorrow, their frustration, with me about my circumstance. Because my email was so detailed that they couldn't miss it. And so, that's how I got the ball rolling on finally being able to have a conversation with Johns Hopkins Wilmer Eye Care Clinic²⁰ to start the process of having eye surgery, because what I did—what I learned was that: due to the inflammation—I had to have a—I had a dense cataract²¹ that developed in my eye. Because COVID has a way of—anything that's wrong already—or that it's happening in your body already—some people with COVID or Long COVID will tell you that it just speeds it up. So, there was a—there was a sign months and months and months ago, you know, before that, of me having a small cataract. Because I don't have great vision in this left eye. But the doctor said, “Oh, you just

¹⁵ Kristerfer Burnett is a city council member of Baltimore representing District 8. He was first elected in 2016 and serves on the council's health committee. (“Kristerfer Burnett.” Baltimore City Council. <https://www.baltimorecitycouncil.com/kristerfer-burnett>. Accessed 13 January 2023.)

¹⁶ Johns Hopkins is a teaching and research hospital located in Maryland dedicated to serving the community. (“About The Johns Hopkins Hospital.” Johns Hopkins Medicine. <https://www.hopkinsmedicine.org/the-johns-hopkins-hospital/about/>. Accessed 13 January 2023.)

¹⁷ St Agnes Hospital, or Ascension Saint Agnes, is hospital in Maryland that offers many different types of specialty care. (“About Us.” Ascension. <https://healthcare.ascension.org/locations/maryland/mdbal/baltimore-ascension-saint-agnes-hospital>. Accessed 13 January 2023.)

¹⁸ Nick Mosby is the president of the Baltimore City Council. He was a previous council member and State Delegate. (“Council President Nick J. Mosby.” Baltimore City Council. <https://www.baltimorecitycouncil.com/nick-j-mosby>. Accessed 13 January 2023.)

¹⁹ Mary Pat Clarke is a former member of the Baltimore City Council and served for a total of 29 years from 1991 to 2020. (“Mary Pat Clarke.” Maryland Manual On-Line. <https://msa.maryland.gov/msa/mdmanual/36loc/bcity/leg/former/html/msa14512.html>. Accessed 13 January 2023.)

²⁰ Johns Hopkins Wilmer Eye Clinic is a subdivision of Johns Hopkins that focuses on ophthalmology. It is ranked #3 in the United States. (“Wilmer Eye Institute.” Johns Hopkins Medicine. <https://www.hopkinsmedicine.org/wilmer/>. Accessed 14 January 2023.)

²¹ A Cataract is a darkened area that is formed over the lens in the eye. It is caused by proteins that become clumped together in the eye. This is more common in older adults. (“Cataract.” Healthline. <https://www.healthline.com/health/cataract>. Accessed 18 January 2023.)

need surgery when you're 50." But because of COVID, I needed surgery at 38-years-old. Which is—which is usually unheard of—

AD: Wow.

CS: —For cataract surgery. And so, that, Abby, started the ball in my activism, and my advocacy for Black women and families with Long COVID. And that is what led me here today, which is why [pauses]. Celebrating [pauses]. A full on. [pauses] Long COVID diagnosis may not mean a lot to most people. [pauses] But it means everything to me. Because I fought extremely hard—

AD: Oh, my gosh—Yeah. Congratulations, that—

CS: —to get it. Thank you. I fought so hard—

AD: That is something.

CS: —Yeah. So hard—

AD: Can you tell me a little bit about how that happened yesterday was that a new clinic?

CS: Yeah. Absolutely. I'm happy to tell you—

AD: New care? Yeah.

CS: I'm happy to tell you—Yeah. Um—I had been seeing a new—I've had to—I've had into the last two years, Abby, I've had three primary care physicians. Because I've had to—I've had to hire and fire. Because what I learned was that: my care is so important: that I have the right, and I have a say on who has care over me. And the other two doctors I had were not willing to acknowledge that I had COVID possibly or that I had this you know post COVID infection, or you know—this illness. And so, I just decided to find me another doctor. And so, I did—I did research. Which is just something prior to getting sick I would have never done. I would have just been like, "Oh, I don't care assign me to whomever— whoever's close. I'm fine."

AD: Right. Right.

CS: But I found this—I found this doctor, and what I liked about her initially is that she had acknowledged my symptoms. She acknowledged the fact that I had all of these symptoms

that came from somewhere. But she never wanted to acknowledge that it came from COVID. So I noticed that—you know—I'd been her patient for a year. And so, I said to myself, I said, "Okay," I said, "You know, there are lots of opportunities for healthcare treatment and management that are cropping up because Long COVID—It's on everybody's lips now, right? Even the President. And Congressmen and -women." And so I said, "If it so happens that I can get, I can be a part of—you know, a treatment or response to Long COVID: I want to be formally diagnosed with it. Because we all know that in March of 2020—I was a first waver. I wasn't allowed to get tested. But the timing and how sick I got—makes perfect sense. And so I've reached out—You know, she and I had a discussion. She said she didn't feel comfortable diagnosing me with Long COVID. And so, I said to myself, I said, "You know what? Let me find the patient relations communication network of Johns Hopkins Community Physicians.²² And I want to reach out to them, so that someone else can review my case and my medical records. And that happened almost like two and a half months ago.

AD: Okay.

CS: So almost three months. So, thank goodness the woman was updating me—the woman I was talking to—she was updating me, and she got the director of the physicians involved. And they started to do some investigating of my symptoms: the timing of my hospitalizations, the medicines I was on, how long I've been out of work—for two years I haven't worked as a teacher—and yesterday she finally sent me an email. And she said, "We are happy to let you know that as of yesterday, we are formally using an ICD code—" ²³

AD: Wow.

CS: "—to diagnose you with Long COVID." And she said, "Based upon our conversations with the Johns Hopkins Infectious Disease Network²⁴ and Johns Hopkins has a Long COVID clinic. Understanding that a lot—"

AD: Right.

²² Johns Hopkins Community Physicians are physicians that provide basic medical care to individuals of all ages in Maryland, Washington D.C., and Virginia. ("About." Johns Hopkins Medicine. https://www.hopkinsmedicine.org/community_physicians/about/. Accessed 14 January 2023.)

²³ ICD Code stands for the International Classification of Diseases. This code, mandated by the World Health Organization, allows for individuals to compare disease statistics from different countries. ("International Statistical Classification of Diseases and Related Health Problems (ICD)." World Health Organization. <https://www.who.int/standards/classifications/classification-of-diseases>. Accessed 24 January 2023.)

²⁴ The Johns Hopkins Infectious Disease Network is a subdivision of the Johns Hopkins School of Medicine that is dedicated to helping resolve infectious diseases around the world. ("Division of Infectious Diseases." Johns Hopkins Medicine. <https://www.hopkinsmedicine.org/infectious-diseases/>. Accessed 14 January 2023.)

CS: “—there are a lot of patients who have had COVID who weren't tested in time—”

AD: Right.

CS: “—so they never tested positive. But because of the timing, because of the symptoms—we had COVID.” So, I was able to get that post COVID diagnosis, as well as a suspected COVID case.

AD: Wow. Wow.

CS: I felt so vindicated yesterday. And I was overwhelmed. And then, finally, as I tweeted out, and I said, you know—because I wanted other people to know that it's possible, right? And so, after that I say—you know—“I'm too overwhelmed to cry,” but as I was tweeting, and people were responding. And I thought about all I had gone through, and I texted my auntie—my favorite auntie, my mama, my best friend. And I said, “this is a victory for me.” I—and my aunt: she responded. And she said, “it is.” She said, “cuz you fought for this.”

AD: You fought hard.

CS: And I said, “I did fight for it.” I fought, fought for it.

AD: Yeah—wow.

CS: Mm-hmm [pauses briefly]. And this is what my advocacy is about. But it's not just for me; it's for other Black women who experienced this, because I used to be on the outside of the landscape. My best friend has a neurological condition. And she wasn't acknowledged for years, and I would listen to her stories. And I would say. I would—I would be on the outside, I say, “Oh, girl that's so sad.” I know women with endometriosis²⁵ who never—who didn't get correct diagnosis until five and seven years after their initial illness and—and I understand now what they're experiencing. Because I had to do the same thing; I had to provide evidence. I had to write emails; I had to write letters; I had to, I did not give up on what I knew to be true. And this is the reward for that. But it's so sad, Abby, that we live in the country as everything is happening now, right? Where women still have to prove—like

²⁵ Endometriosis is a disorder where the tissue lining the uterus, known as the endometrium, is growing outside of the uterus. It is very painful and can be difficult to get a diagnosis. (“Endometriosis.” Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/endometriosis/symptoms-causes/syc-20354656#:~:text=Endometriosis%20is%20a%20condition%20in.including%20the%20bowel%20and%20bladder>. Accessed 15 January 2023.)

lawyers. I might as well have gotten my law degree. [Laughs]. You know? Damn teaching! I might as well say I'm a lawyer.

AD: Right [laughs].

CS: Cuz I had to prove, in writing, with a sore head, with limited vision, with achy hands, an aching body—with a body that was crumpled up like paper on some days. In the dark—that I was as sick as I was.

AD: Wow. What do you hope will come with this day-old, now, diagnosis? Do you have hopes for what it might make possible?

CS: Absolutely um—as I mentioned, you know, it remains to be seen on a political policy level. But, you know, we do know that there's a Long COVID movement happening, right? That was galvanized by a bunch of women who were sick was Long COVID. You know—shout out to the men, but oh my goodness: the voices on Twitter,²⁶ and social media, and Long COVID groups were resoundingly women, right? Who were telling their stories, and so I do know as a Black woman how hard it is to tell our stories, because there's so much fear around being rejected or not heard. And so I'm hoping that my victory will lead to other Black women seeking the same kind of care. You know, not backing down—

AD: Right.

CS: —Just because a doctor says, “Oh, it's this and it's not that.” Because if I had let—Who, I really care for. I love her. She's a great doctor. but she just—Long COVID is so new.

AD: Right.

CS: And it's so nuanced that there's so much more to learn. And so, if I had been settled with what she was saying: If I were to say, “Hey, I want to be a part of NIH's²⁷ trial and clinical trials for anti you know virals or whatever treatment.” I couldn't be because they would need specific paperwork to say that I'm a Long COVID patient.

AD: Right. Right.

²⁶ Twitter is a social media site founded in 2006 where users can send tweets, which can consist of messages, images, or videos. (“Twitter.” Wikipedia. <https://en.wikipedia.org/wiki/Twitter>. Accessed 15 January 2023.)

²⁷ NIH, or the National Institutes of Health, is a United States government agency founded in the 1880s that is dedicated to public health and medical research. (“National Institutes of Health.” Wikipedia. https://en.wikipedia.org/wiki/National_Institutes_of_Health. Accessed 15 January 2023.)

CS: Right? Any way I'm treated going forward—doctors have to acknowledge that first. And so that could be the difference—like I said in my Facebook²⁸ post yesterday—that can be the difference between some care and better care.

AD: Nice. Yeah.

CS: —and over the last two years I've learned that I am—I am deserving. And have the right to better care.

AD: Yeah, that's a nice distinction there. Yeah. That's really powerful.

CS: And really that's what I want for myself—that's what I want.

AD: Right.

CS: And not only for myself: I want that for all of us.

AD: Right, because it sets a precedent.

CS: It does.

AD: Right.

CS: It does, yep.

AD: And that does seem to be such a hurdle for so many patients is—

CS: Yeah! Two years later that—

AD: Not having—

CS: —right.

AD: —that documentation of a positive test.

²⁸ Facebook is a social media website founded in 2004 where users can post photos, videos, and messages for the public to view. ("Facebook." Wikipedia. <https://en.wikipedia.org/wiki/Facebook>. Accessed 15 January 2023.)

CS: Right. And that's why I always tell people now especially—you know—I'm a part of some wonderful beautiful Black Long COVID networks now. And I tell those women and those groups, I said, "Keep everything. And make sure—keep every medical document to be more specific—and make sure that those doctors, even if they do not necessarily believe, that they believe that you have Long COVID please ask them to put it in your medical records that you suspect that you've had COVID, and now Long COVID. Because somebody needs to see it. And one day somebody is going to see it, and they're going to believe it. And then that could be the key and the ticket to better health care.

AD: Can you tell us a little bit about these Long COVID networks that you're part of—

CS: Absolutely! Yeah—

AD: —and the work that's being done?

CS: Yeah, absolutely. I am a part of [Dr. Margot Gage's BIPOC²⁹ long-hauler, Long COVID women's group.](#)³⁰

AD: Okay.

CS: Which is one of the first pioneering [BIPOC](#) Long COVID groups for women that really focuses on women of, that are not—you know—non-white. You know, there's a—there's a safe space for us there. She—What I love about her group is that she herself has experienced COVID, and some of the effects of Long COVID. She's an epidemiologist in Texas³¹ at Lamar university.³² So, she brings a wealth of statistical data that she's always sharing with us. She's very protective of our group; she's like the mama bear. Because she doesn't allow her group to get used by organizations who just want to tokenize a BIPOC group. There is—there are connections being made there every day; there's great advice there. Great friendships have been formed from that group; great ideas. Brilliant women

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²⁹ BIPOC is an acronym that represent Black, Indigenous, and people of color. ("Why We Use BIPOC." YWCA. <https://www.ywcaworks.org/blogs/ywca/wed-04062022-0913/why-we-use-bipoc#:~:text=DEFINITION,solidarity%20between%20communities%20of%20color>. Accessed 15 January 2023.)

³⁰ This women's group refers to a Facebook group started by Dr. Gage for BIPOC women affected by Long-COVID. ("Frayed Pages." Twitter. <https://twitter.com/frayedpagesent/status/1504913365382144008>. Accessed 24 January 2023.)

³¹ Texas is a state in the United States located in the south. It is bordered by the Gulf of Mexico to the southwest and is known for being one of the most populated states in the country. ("Texas." Wikipedia. <https://en.wikipedia.org/wiki/Texas>. Accessed 15 January 2023.)

³² Lamar University is a higher education institution located in Beaumont, Texas. It is a public research university and consists of 5 undergraduate colleges. ("Lamar University." Wikipedia. https://en.wikipedia.org/wiki/Lamar_University. Accessed 15 January 2023.)

are in that group. And women who really—who are becoming sick with Long COVID; that's a group for women to come to get loved and cared for, and to even get advice.

AD: Wow.

CS: Because still—two years later—doctors can't tell us how to take care of ourselves, the way we can tell each other how to take care of each other. And so, there's a—there's a sense of family and community in that group. And of all the groups I've been a part of—I've been a part of some *amazing* groups. But I was looking for a group that represented me, that when I—when I was a part of the group, I saw myself.

AD: Yeah.

CS: That is the group that I chose to—I choose to be the most active in right now. And I can't—I can't wait to see more exciting things that we do together in the next year, so.

AD: Wow. That sounds really powerful. What platform does the group use? Is it all virtual?

CS: Yes, it's Facebook. She has a Facebook group. Uh huh—yeah.

AD: Amazing. And then, we mentioned that you're also a new volunteer with #ME Action.

CS: Yeah.

AD: Do you want to describe that work a little bit?

CS: Absolutely. You know, what's so interesting is that when I first got sick, I was introduced to another pioneer in the chronic illness world. Her name is Wilhelmina

Jenkins.³³ She's a Black woman who lives in Atlanta,³⁴ Georgia.³⁵ Wonderful woman, who has ME [myalgic encephalomyelitis],³⁶ right? And she—which is another chronic illness—and I love my connection I gained from her. Because, she was one of the first people in #ME Action, who acknowledged the fact that a lot of us were suffering from some of the same symptoms—as chronic fatigue syndrome, or other exhaustion-inducing chronic illnesses. So, I thought that was interesting that a group would come out and show so much support for Long COVID patients, because they were seeing that in a post-viral world in our conditions that we were suffering from the same, some of the same symptoms. And so, I met her; I met a woman in California³⁷ named Ashanti Daniel.³⁸ And those women were a part of #ME Action. And so, they were two of the first Black women to actually talk to me and talk to a couple of other of us to say, “Hey, you might need to consider either reducing your hours at your job, or leaving your job.” And I was devastated to hear that at first, because I was like, “what they mean—what you mean quit my job? I *love* teaching; I *never* leave.” You know what I mean? Even in the—even in August of 2020 when school was about to start again virtually I was like, “I’m going back to work; I’m going to feel better.” But I felt horrible in August. But these women actually came and talked to me and a few others and said, “Hey, we’ve seen this before; here’s how we can support you.” And they kept stressing this whole, “stop, rest, and pace” formula that would help to alleviate some of the exhaustion, right? And I was like, “I don’t want to do that.” But I found that the more I rested after activities or before activities, I started to feel a little bit like myself again. And so—It wasn’t so much that I was looking for—to be a part of #ME Action. I think that every—the stars aligned that I met great members of me action first. And so, then, by the time this year happened, and they approached me about this wonderful opportunity to help engage a more racially diverse volunteer, I had to—I had to say, “yeah.” Because that group was one of the first groups that embraced the Long COVID community. And the truth of the matter is a lot of these health organizations need to have a

³³ Wilhelmina Jenkins is an activist for the recognition of ME (Myalgic Encephalomyelitis) and is a volunteer at #MEAction in Georgia. (“#MEAction Volunteer-Of-The-Month: She’s Been Fighting For Change For Four Decades.” #MEAction. <https://www.meaction.net/2019/09/06/meaction-volunteer-of-the-month-shes-been-fighting-for-change-for-four-decades/>. Accessed 18 January 2023.)

³⁴ Atlanta is the most populated city located in Georgia. It is also the capital of Georgia. (“Atlanta.” Wikipedia. <https://en.wikipedia.org/wiki/Atlanta>. Accessed 18 January 2023.)

³⁵ Georgia is a state in the southern United States. It is known for being one of the most populated states in the country. (“Georgia.” Wikipedia. [https://en.wikipedia.org/wiki/Georgia_\(U.S._state\)](https://en.wikipedia.org/wiki/Georgia_(U.S._state)). Accessed 18 January 2023.)

³⁶ ME, also known as Myalgic Encephalomyelitis, is a syndrome that often affects individuals’ daily lives. Symptoms of ME include fatigue, issues with sleep, and dizziness. (“What is ME/CFS?” Centers for Disease Control and Prevention. <https://www.cdc.gov/me-cfs/about/index.html>. Accessed 18 January 2023.)

³⁷ California is a state in the United States that is bordered by the Pacific Ocean in the west. California is known for being the most populated state in the United States and is home to several highly populated cities as well. (“California.” Wikipedia. <https://en.wikipedia.org/wiki/California>. Accessed 18 January 2023.)

³⁸ Ashanti Daniel previously was a Registered Nurse, but now is an advocate for individuals with Myalgic Encephalomyelitis. (“Ashanti Daniel, BSN, RN.” Social Health Network. <https://www.wegohealth.com/49469947>. Accessed 18 January 2023.)

more diverse population of people. Board memberships, active members and volunteers. Staff members. Paid staff members. Internships. There needs to be a plethora of a BIPOC representation in these organizations. And there's—there are many reasons why they're not. But, I would like to at least start the conversation. Because, I spent a lot of time over the last two years being angry, right? About being the only Black woman, or the discarded Black woman, and I have sung that song—and I still feel that way. But over the last six months I started to think about—[long pause]: My mission. My purpose. And I have a niece who will be a year old this Sunday.

AD: Oh my gosh!

CS: Monica. And I said to myself, “One day. Monica is going to find this information about her auntie. And—and the legacy, because she’s the only”—I don't have children, I don't plan on having children of my own—she's the only girl in the family that's going to be building our legacy.” Right? And I said, “One day she's going to look at stuff about auntie, and she's going to wonder did auntie stay the angry Black woman.” Or did auntie—[long pause]—cultivate a mission and a purpose, where she could still be angry. But that she could do something instrumental and constructive with her anger. And so, instead of continuously saying, “All these white groups—they just—I don't see any Black people.” I said, “You know what? Like my friend Liza Fisher,³⁹ who also has Long COVID said, ‘I want to be the disrupter in the community that doesn't have representation and looks like me.’” And so I decided to disrupt in a different way.

AD: Wow, that's really inspiring.

CS: Thank you.

AD: Have you figured out how to—how to sort of build on—you've mentioned being tired in a range of ways.

CS: Yeah.

AD: But the physical exhaustion of continuing to feel unwell, and the energy that it takes to blaze a path in that way: Do you have strategies for—Is it still sort of resting and pacing? Is that how you sort of move forward—

³⁹ Liza Fisher was previously a flight attendant before her long-COVID diagnosis, and is now an advocate for long-COVID by documenting her journey with long-COVID on her Facebook page. (“Liza Fisher: Long COVID (Health & Veritas Ep.12).” Yale Insights. <https://insights.som.yale.edu/insights/liza-fisher-long-covid-health-veritas-ep-12>. Accessed 18 January 2023.)

CS: Absolutely [laughs].

AD: —the work that you're doing?

CS: Absolutely! It takes—I definitely strategize my schedule. And I am—I am so [short pause]. The good thing about my being a teacher is that: I already came a little bit equipped with this, right? Because, as a teacher, I was very much a stickler of time: How long classes went, when they began, when they ended, lunchtime, recess, all of those things. And so, I have become even more of a stickler about me. And understanding that in order for me to be present, I have to rest. There are days, Abby, where, there are days at a time when I have to—this couch! It's Chimmy's couch. This couch will transfer into my bed. Because I understand that, in order to move a little bit, talk a lot—whatever it is I have to do on any given day when I can do it, right? —Is contingent upon when I can do it and—

AD: Right.

CS: —if I can do it. I have to rest. Resting has to become—resting has become—Let me say it like this: Resting has become my primary job. And it's interesting as a woman, because most of us, and especially as I look at how our country operates. I was talking to somebody the other day, who said, “Oh, my goodness, you know, I miss working 100 hours per week.” And I thought about my life as a teacher, and I would come into the school building at 6:30am. I wouldn't leave until 6:30pm. I would stay as long as I could; I would be there on weekends. I would be planning lessons on Saturdays and Sundays, when I should have been out enjoying myself. I wasn't resting like I should have. I wasn't take—we don't practice that anyway.

AD: Right.

CS: So, what I've had to learn how to do: is to make resting my number one priority. Even to the [chuckles] dismay of family, friends, loved ones, and people who just have that idea of [gestures with pointer fingers spinning around one another] going, going, going.

AD: Right.

CS: I can't afford to do that, because if I go, go, go, go, I will be sick, For days, or weeks or months at a time.

AD: Right. Right.

CS: And um—I don't want that. I have post-traumatic stress disorder⁴⁰ now. So, the whole idea of me putting myself at risk, because I've overextended myself for someone else.

AD: Right.

CS: And I don't understand the word, “no.” That scares me. So, oftentimes I'm scared into resting—because I'm like, “Look—can't anything stop me from resting. Because I'd rather lay on this couch for two days than speak at this event, or that event, or go do this, and do this.” And then for two weeks I'm down for the count.

AD: Right.

CS: You know, which is what a lot of us are still suffering with two years later.

AD: Exactly. So, would you say that's your primary symptom at this point, is fatigue?

CS: No, it's not.

AD: No?

CS: Actually, I have—I have a lot of things going on with me.

AD: The list—the list continues.

CS: And that's the interesting part about invisible illnesses, is that: if people don't see it, they don't believe it.

AD: That's right.

CS: Um, but I have chronic migraines⁴¹ now.

⁴⁰ Post-traumatic stress disorder, or PTSD, is defined as a mental health disorder in which a traumatic event can cause anxiety or repeated memories of that event. (“Post-traumatic stress disorder (PTSD).” Mayo Clinic. [https://www.mayoclinic.org/diseases-conditions/post-traumatic-stress-disorder/symptoms-causes/syc-20355967#:~:text=Post%2Dtraumatic%20stress%20disorder%20\(PTSD\)%20is%20a%20mental%20health,uncontrollable%20thoughts%20about%20the%20event](https://www.mayoclinic.org/diseases-conditions/post-traumatic-stress-disorder/symptoms-causes/syc-20355967#:~:text=Post%2Dtraumatic%20stress%20disorder%20(PTSD)%20is%20a%20mental%20health,uncontrollable%20thoughts%20about%20the%20event). Accessed 18 January 2023.)

⁴¹ Chronic migraines are severe headaches that occur frequently over an extended period of time. Symptoms include dizziness, nausea, and pain in the head. (“Chronic Migraine.” Cleveland Clinic. <https://my.clevelandclinic.org/health/diseases/9638-chronic-migraine#:~:text=What%20is%20chronic%20migraine%3Fa%20more%20frequent%20headache%20pattern>. Accessed 18 January 2023.)

AD: Okay.

CS: I get about 10 to 20 migraines a month.

AD: I'm sorry.

CS: I have something called Occipital Neuralgia,⁴² which affects the back of my brainstem. It can sometimes cause burning of my scalp—around my temple area, my shoulders, my neck. Sometimes it affects my ability to swallow and speak. And it causes a lot of sinus pressure so—those are two of my biggest symptoms that causes blurry vision, confusion, memory loss, um—and that also feeds into the exhaustion.

AD: Sure.

CS: Migraine sufferers are usually exhausted. And so, that also—have developed. I'm in the process of looking for a rheumatologist⁴³ now because I'm only 40, and I have developed—because of the inflammation in our bodies—I have developed, it feels like arthritis in my hands, and my fingers—and my ankles, and my feet, my toes. I had deep muscle pain at times. To the point where—sometimes moving is difficult.

AD: Are there any particular muscles where that tends to—?

CS: Arms—in my arms; in my shoulders. It feels like—and I used to go to the gym all the time to get summer ready—and even exercising is difficult for me now, right? So, you know that soreness of working out? I get that soreness once or twice a month, and I haven't been to a gym in like three years. It's just our bodies are so inflamed. When I take any—when I do any blood work they always say, “the inflammation is still pretty high.” And it's everywhere. Also, now—get these chicken pox-like⁴⁴ rashes on my body. I don't know if you can see—[moves tank top band over to show]—there's one.

AD: Oh—uh huh.

⁴² Occipital Neuralgia is a type of headache in which there is severe pain in the back of the neck, head, and ears. It can be treated with rest and massages, (“Occipital Neuralgia.” NIH. <https://www.ninds.nih.gov/health-information/disorders/occipital-neuralgia#:~:text=Publications-Definition,neck%20and%20then%20spreads%20upwards>. Accessed 18 January 2023.)

⁴³ A rheumatologist is a doctor that specializes in autoimmune illnesses, illnesses that affect the muscles, bones, joints, tendons, and ligaments. (“What is a Rheumatologist?” American College of Rheumatology. <https://www.rheumatology.org/I-Am-A/Patient-Caregiver/Health-Care-Team/What-is-a-Rheumatologist>. Accessed 18 January 2023.)

⁴⁴ Chickenpox is an infectious viral disease that produces a rash with blisters. (“Chickenpox.” Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/chickenpox/symptoms-causes/syc-20351282>. Accessed 18 January 2023.)

CS: And there are many—All around. I mean, I've never—I've always came—I, you know, I used to have eczema.⁴⁵ That was my biggest thing, but now, those are everywhere on my body. On my ankles, on my booty, on my legs, on my thighs. And I say, "Lord." I mean this is—it's ridiculous.

AD: Wow. So, the list that you had in 2020 has changed. I mean, the list is still long, but those symptoms have sort of changed over time.

CS: Yeah, and that's the thing that—that people need to remember. Is that—and I caution—there's caution when I say, "One thing may become resolved, right? But there is going to be something else that crops up." So you may not have the body pain. But I just read a study this morning that talked about or—not a study I'm sorry—I just saw a tweet from a doctor, who treats dementia⁴⁶ patients and Alzheimers⁴⁷ patients, who said that they've never seen like this before: a memory loss issue like we've seen with Long COVID. And they treat people who have memory loss. But they are also doing studies and tests, and they're seeing such a large number of people with Long COVID or post COVID, who have memory issues. But you almost trade one for the other, and it's sad.

AD: Mm-hmm. Mm-hmm [short pause]. I've been struck by how much you've described the support that you've had from other women. And I guess the segue for me, question-wise, would be to think a little bit about feminism. How you understand the term? What it means in your current work now? Whether you consider yourself to be a feminist? I'd be curious to hear your thoughts.

CS: I think about that often. I was blessed to be able to study feminism, Black feminism, you know—at Morgan State University⁴⁸—Go Bears!—in Baltimore Maryland, under a woman

⁴⁵ Eczema, or Atopic Dermatitis, is a condition that is defined by dry and itchy skin. It is more common in young children and is usually lasts for a long time. ("Atopic dermatitis (eczema)." Mayo Clinic. [https://www.mayoclinic.org/diseases-conditions/atopic-dermatitis-eczema/symptoms-causes/syc-20353273#:~:text=Atopic%20dermatitis%20\(eczema\)%20is%20a%20irritating%20but%20it's%20not%20contagious](https://www.mayoclinic.org/diseases-conditions/atopic-dermatitis-eczema/symptoms-causes/syc-20353273#:~:text=Atopic%20dermatitis%20(eczema)%20is%20a%20irritating%20but%20it's%20not%20contagious). Accessed 18 January 2023.)

⁴⁶ Dementia is defined as the weakened ability of cognition and decisions that relate to daily activities. Dementia mainly affects older people. ("About Dementia." Centers for Disease Control and Prevention. <https://www.cdc.gov/aging/dementia/index.html#:~:text=Dementia%20is%20not%20a%20specific,a%20part%20of%20normal%20aging>. Accessed 18 January 2023.)

⁴⁷ Alzheimer's disease is defined as a neurological illness in which the brain begins to shrink and subsequently brain cells begin to die. It is known to be one of the main causes of dementia. ("Alzheimer's disease." Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-20350447>. Accessed 18 January 2023.)

⁴⁸ Morgan State University, also referred to as MSU, is a public research university located in Maryland. It is known for being the largest historically black college and university in Maryland. ("Morgan State University." Wikipedia. https://en.wikipedia.org/wiki/Morgan_State_University. Accessed 18 January 2023.)

named Dr. Sheffey,⁴⁹ and so many other beloved professors [long pause]. And so, I have my own version and view of what I believe feminism is. And I think it is an outrageous, sensational, yet overtly intelligent fight for all women. Right? I never saw myself as a feminist. I would read books about Maya Angelou,⁵⁰ and—Terry McMillan,⁵¹ I'm sorry, Toni Morrison,⁵² and read books where we explore the ideas of feminism: the suffrage movement, burning bras, and you know—protesting down streets. And I never saw myself as a feminist [long pause]. I don't know if I think I'm deserving of the—of the label. But what I will say is this: in order to—People tell me this often and I've always had issues with receiving love and receiving flowers, you know. People giving me things. And this has been especially difficult for me for the last two years, because there have been such a such a large number of women and people who are DM'ing (direct messaging) me and sending me emails. Sending gifts and support who are like, "oh my God you helped save my life," and, "if it hadn't been for you," and, "I'm encouraged by you." And I'm just like, "Me? Little old me?" Like—who never used to want to—you know. I would never like to start confrontation. I always wanted to be seen as the good Black girl. But when I think about what I've had to do to bring awareness as one of the very first Black women to talk about the Long COVID experience. And what I've had to do to speak about the health rights—of Black women was Long COVID. It was outrageous. Because I was doing something that historically I would never have done. I was also doing what a lot of Black women are forced not to do. It was sensational, because I used my experience with a condition that was unheard of practically at that time—to get my point across. It was bold. It was brazen. And that's what feminism is to me. All of those things, even in the ugliness of it. Whether it's real or perceived. To open up a door for some part of women's rights. And I think in order to be a feminist, you have to be willing to be outrageous, sensational, intelligent, brazen, bold. Because—there's always going to be an avenue, a layer, a lane, in which we have to fight for the rights of women. The doors never close. We see it to—we see it today. And historical times that we live at.

AD: Yeah.

⁴⁹ Dr. Sheffey is an English professor at Morgan State University who is known for her long-standing impact on influential authors like James Alan McPherson, who was won the Pulitzer Prize. ("Ruthe T. Sheffey, PH.D." Morgan State University Foundation, INC. <https://givetomorgan.org/donor-stories/ruthe-sheffey/>. Accessed 18 January 2023.)

⁵⁰ Maya Angelou was a civil rights activist and a poet. She was given many awards for her essays and poems over the course of her life and is known mainly for her autobiographies depicting her early life. ("Maya Angelou." Wikipedia. https://en.wikipedia.org/wiki/Maya_Angelou. Accessed 18 January 2023.)

⁵¹ Terry McMillan is an American author who mainly writes about the experiences of Black women. She had published 11 books and has had 3 of her works adapted to television. ("Terry McMillan." Wikipedia. https://en.wikipedia.org/wiki/Terry_McMillan. Accessed 18 January 2023.)

⁵² Toni Morrison was an American author who has won multiple notable awards, such as the Pulitzer Prize and Nobel Prize in Literature, for her works. Morrison's publications were mainly about racism in the US. ("Toni Morrison." Wikipedia. https://en.wikipedia.org/wiki/Toni_Morrison. Accessed 18 January 2023.)

CS: And so, I see myself [long pause]. I hate to say it, gosh. And I think it's a part of being a woman is that we want to—we've been taught to—especially a Black woman. I've been taught that in order to be successful in this country—that the more demure, quiet, covertly successful or—to hide what I know, who I am, and what I can bring to the table. I've been taught that to be successful—to do that as a Black woman. And yet, everything I had to do over the last two years to get here. I had to break every single one of those rules. So, I would call myself a feminist. I would. Because my mission has never changed. It's always been about the education, the visibility—the representation—of Long COVID experiences coming from Black women. I care about all women, I care about all people, but I live in this body. And I know what it's like to be me. And when I talk to other Black women our stories are—It's almost like we wrote a script. Because in this space is a lot of our stories are the same.

AD: So powerful.

CS: Thank you.

AD: And really connects with how we were going to wrap up the interview thinking about gender health and Long COVID and—

CS: Yeah.

AD: —particularly in the context of Long COVID—what your experiences and work because sort of revealed about the intersectional dimensions. Whether that's gender, race, class, ethnicity. And what Long COVID can tell us a little bit more about gender, health, and medicine in the US.

CS: Absolutely. I—you know what's so funny is that—Like I said, I realized in June 2020 that I had to—If I was going to do this, it was either going to be go big or go home. And so, my “go big,” was to speak to the media, to speak to everybody, to speak to as many people who would listen. And I have to shout out Fiona Lowenstein,⁵³ um—who's now about to publish the first Long COVID Survival Guide. I'm really proud—which I wrote a chapter in—who as a white woman, she used her platform, and her visibility, and she passed the torch to me. Because in like the end of May, early June, when she was texting—you know—she was saying, “Hey, I want you to interview with such and such. I don't think they need to

⁵³ Fiona Lowenstein is a journalist and the founder of Body Politic, an organization dedicated to health justice. Their work has been published in many notable newspapers, such as The New York Times and The Guardian. They are also an interviewee of the Global Feminisms Project. (“Meet Fi.” Fiona Lowenstein. <https://www.fionalowenstein.com/about-3>. Accessed 18 January 2023.)

see another white woman; I want—I want—you've been speaking about this. I want you to go on such and such." And that afforded me the opportunity to go on MSNBC,⁵⁴ on the Today Show,⁵⁵ I mean all these different platforms and stuff, which I'm grateful for, but one of the most important conversations I had about the intersectionality of gender, health, race, and class, was when I told Representative Anna Eshoo⁵⁶ in California that I was a poor Black Disabled woman in Baltimore. I wanted to cover as much of that intersectionality as I could. Because most times people don't tell it as real as that. You know, they want us to hear about, "Tell us about your symptoms and what you go through on a daily basis," and I was like, "Fuck that." I'm not—I've told that story too many times.

AD: Right.

CS: What I want you to see—Is that I was a teacher making almost \$70,000 a year. And in less than a year—I'm not even making a quarter of that. I wanted them to know that I played all of my cards right in being a successful Black woman, right? They tell us to, "mind our manners. Go to school. Get a degree. Get the house. Move out the hood. Get married. Have children. Be quiet. Don't say much. Don't challenge your bosses. Don't challenge the system." I did all of that. Except for the house and the marriage—and the kids [laughs]. Although I did gain about 100 [kids], 'cause I taught school. And—and the stuff that I was supposed to get for playing the good Black little girl, I did not get. I did not get acknowledged with my blue and white insurance card. I'm—I'm looked at today, with all the education, with all of the of the achievement as a teacher, when my school system sent me my letter telling me that my contract wasn't renewed, They didn't say it was because they understood—because I had Long COVID. They said it's because I hadn't been present in my job. Because I've been sick. People don't think about the cross lanes and sections of being all of these things combined into one. And so, every time I speak, I want people to know what this looks like. I don't want people to ever look at me and not hear me say, that today I live on a social security check of 1600 dollars a month, when rent—for most of us in this country—is \$2,000 a month. I never want people to not hear me say that Long COVID has disabled me. I never want people to not hear me say that the ecosystem that I created to supply and provide for my mother—who will be 65 this year--was completely eradicated when I got sick. My goal was to make enough money, to teach for another five years, to

⁵⁴ MSNBC is a cable channel owned by American company NBCUniversal. MSNBC is covers news and politics in the United States. ("MSNBC." Wikipedia. <https://en.wikipedia.org/wiki/MSNBC>. Accessed 24 January 2023.)

⁵⁵ The Today Show is a morning news/talk show on the NBC channel. It is known for being one of the longest-running series on American television. ("Today (American TV program). Wikipedia. [https://en.wikipedia.org/wiki/Today_\(American_TV_program\)](https://en.wikipedia.org/wiki/Today_(American_TV_program)). Accessed 24 January 2023.)

⁵⁶ Representative Anna Eshoo represents the 16th congressional district in California and currently is on the Health Subcommittee and is known for her work in promotion access to healthcare. ("About Anna." Congresswoman Anna G. Eshoo. <https://eshoo.house.gov/about-anna>. Accessed 18 January 2023.)

become a principal or school leader, and send my mama money every month to assure that she was taken care of. My mama didn't go to college. She's worked all her life. She has two children, and my goal was to work hard enough to help her pay for something: a bill, or for rent or something. Because I had finally made it. And, in less than a month, in March of 2020—the ecosystem collapsed.

AD: That's so devastating.

CS: So, we do need to start thinking about race. And gender. And class. And how everything becomes disrupted when stuff like this happens. We don't think about it enough, we don't even talk about it. We can't be reactive to this.

AD: Right. That's right.

CS: We have to be proactive; we don't talk about

AD: Right.

CS: what happens when things like this devastate. All of those—of those topics. Mm hmm. Yeah.

AD: I'm so sorry.

CS: Thank you. Yeah. Thank you, I appreciate that.

AD: Yeah. Yeah—Do as we sort of—as we wrap up—

CS: Sure—

AD: —and sort of leave on these thoughts. Is there a vision of a future at this point?

CS: Yeah. It is. Um, and I'm so glad that there is. I've—And this may not sound—This may not make sense to a lot of people, because I think what happens with—It's just like being a woman, right? You know, we have our families, our partners, our jobs, our careers, our missions, our purposes, and we will wear ourselves out trying to make everything happen. Doing so much for other people. And not saying—not knowing how to say, “no.” And not knowing how to do things for ourselves, and not taking the right amount of time for ourselves. But what this has taught me, and I've learned so much. And this is such a cliché. I'm learning so much about myself over the last two years. And I've had to be so patient and gracious with myself. I mean, you're looking at a woman who could not walk for nine

months. Like without some type of aid, or couldn't stand for a long time. And I had to teach myself, really, how to walk again, right? Long COVID is a part of my life now. But it is not my life. And so, my vision for my future is—is a vision where there is adequate treatment, a management of symptoms. For myself and other Black women, other people period, but really for Black women. Especially those of us who live in urban, low-income neighborhoods like the ones I have been a part of my entire life. Where I taught. But my goal is to also enjoy my life [pauses]. And—it is going to sound so bizarre [pauses again]. But I love my life. And so, even when it comes to advocacy and activism. I no longer feel guilty when I can't commit to everything. Because I used to never prioritize myself; I used to be a big people pleaser. And yet, one of the biggest lessons I've learned the last two years, Abby, is that I can act, I can advocate, but I have to be the first person I advocate for. And so, my future is bright, because, you know—I'm on the right antidepressants now. So, I don't suffer as much with depression like I used to. You know I'm working with organizations that are really trying to find ways to help Long COVID patients. I feel good about those things; I feel good about my volunteerism. But I am also stopping outside when I can, to smell the flowers; to look at the trees; to be thankful for every moment that I'm here; to be thankful for a Long COVID diagnosis-- the small things. Because I never want my voice of advocacy to be louder than the love and the care that I give to myself. Some people are killing themselves in advocacy too.

AD: Right, right, right. No, that's a really beautiful message.

CS: Yeah, and they don't rest.

AD: Yeah.

CS: And so, that's my goal for myself. My goal is to really take the best care of myself. Eating better. Trying to walk a little bit more. Taking my medicine on time. Being around, if I can—because I'm deathly afraid of getting COVID again—people that I enjoy. Reading and—and one day falling in love you know? [laughs]. Again. Because, you know, I'm a roman—I'm a hopeless romantic. And so, those things. And writing more. Because I have a—you know—I want to write an article, you know, soon about what it's like, you know, how long COVID helped me to realize I don't want kids. And so, there are lots of things left for me to do.

AD: Yeah.

CS: And advocacy is not just, [raises hand into fist and pumps it while saying] “power to the people!” Right? It is writing about that.

AD: Right.

CS: It's showing up for #MEAction. It's being a better best friend. It's speaking, you know—having a focused mission, which is—which over two years I didn't have until now. And so, that's what my future looks like. Being there for my niece [chuckles happily]. Telling her about this—

AD: Your one-year-old niece.

CS: Yeah, my future—on some days it looks grim. But on most days it looks bright.

AD: I'm so glad to hear that.

CS: Thank you.

AD: Thank you so much for—

CS: Thank you! I hope I didn't talk you half to death!

AD: —joining us. Oh, my gosh, no. It was such an honor to interview you.

CS: Thank you.

AD: It's an inspirational story. Thank you so much for being willing to share it with the Global Feminisms Project.

CS: Thank you. Thank you.

AD: I know so many people will benefit from it.