



Coronavirus: Wisdom from a Social Justice Lens

COVID-19 Prep for People Living with Chronic Illnesses in the U.S.

JD Davids, Evvie Ormon, Dr. Crissaris Sarnelli, Elandria Williams

[00:00:00] [soft ambient music begins]

Kate Werning: Hey, everybody. This is Kate Werning coming at you in the week between our name change. We've been *Healing Justice Podcast*. Starting on March 16th, we are launching our new name. But in this interim moment, we are coming to you with a special bonus episode, a really important conversation that was convened by a bunch of friends that we really, really trust about COVID-19, the coronavirus, and preparation and coordination between folks living with chronic illness and disabilities here in the United States. It has really impressed me how much this conversation has really come to the center and how important it is for us to be tuning in with the lens of our politics, with the lens of our values on supporting the people in our communities who need the most support in responding to this pandemic collectively and with collective well-being in mind. And how much help I need and how many questions I had about how do I do that in a good way, where I'm tuned into what's happening and am responsible for my health and for my community? And also, I'm not spinning into crisis and anxiety in an over-attuned way, right? [music slowly fades out]

And so I'm super grateful to be sitting here with JD Davids, who is a friend and a longtime sort of team member and buddy of the podcast. And we're going to be sharing with you some of the wisdom through a conversation that JD organized that took place on Saturday, March...7th. [laughs] Whatever today is. And so hey, JD. How you doing?

JD Davids: Hey, I'm okay. I'm a little tired. [chuckles]

Kate: We're tired because we just went through this like four-hour experience of hosting this webinar. You've been hustling to pull this together in a rapid response way for a week and a half, yeah?

JD: More like a week, but, yeah. [laughs]

[00:02:00] **Kate:** A week! Can you tell us a little bit about your inspiration to pull this together and sort of what happened when you put the call out?

JD: Well, I've been a part of networks of people living with chronic illness or disability, particularly HIV, for a lot of my life. And I've seen the power of people who know what they know and know what they need, changing their circumstances, changing the world and in a way that helps everyone. So what I've seen how this has been rolling out, I wanted to do what I felt like I could do knowing what I do know, which is to put out a call for help.

Kate: Mm. And what is the response that you saw?

JD: Well, we pulled together this call for a webinar, which meant that people were gonna be able to be together online: some people on video where they could look at a chat room and see each other's faces, some people who could be on by the phone. And the first registrations started coming in five days ago. And ultimately, it's been about 1,000 people so far that want to be a part of conversations or get the follow-up information or be a part of an ongoing network that really centers the experiences and knowledge of people living with chronic illness and disability. So I'd say that's [affirmation] pretty, pretty big. [laughs]

Kate: Pretty big. I mean, seriously, in five days.

JD: Yeah.

Kate: And you put this out through [The Cranky Queer](#), which is like, in the years that I've known you, you've been talking about this as has been very much your actual life and the seed of the work that you do for a long time. But it's only in the past few weeks, really, that it's become a thing online and that people can find The Cranky Queer on social media and follow your writing and more consistently through your newsletter. Yeah. Will you tell us [00:04:00] a little bit about The Cranky Queer and your vision for that?

JD: Yeah. So I'm The Cranky Queer because we've already reclaimed "queer." So now I'm reclaiming "cranky." And I'm working on a book called *The Cranky Queer Guide to Chronic Illness*. What I found as a person who's been living with chronic illness most my life to some degree or another, is that--and who's been a healthcare activist and a queer activist most my life now, too--is that the way larger systems of care, information, the media, politics talks about health, illness, wellness, medicine, systems of care and all of it, well, we know there's lots of problems. But in particular, what I've saw, which also included working in digital health media, is that the way we can access information, or at least I've been able to access information, didn't really serve me. Because people are sliced and diced into what kind of healthcare provider specializes in a diagnosis they may have, or people often can't get a diagnosis if they don't have resources and certain kinds of privilege. Or it might be

about if you have a condition that has a treatment that is expensive and patented, then pharmaceutical companies are going to buy space and ads and sometimes actual content from online health resources. And so you'll find a whole lot of information, I would say "information" with air quotes, though, because often, it's the same kind of article over and over because it fits the mandates of sometimes of what the advertiser wants.

I mean, you know, there's a lot that I sort of, every, all of us who deal with chronic illnesses or disability, we have our own path, right? And on our path that we've often had to pave on our own, we've learned a lot. And we do a lot, and we support each other a lot. And so I'd like to share some of the things that I've been thinking about, wondering about, or learned and to hear from others.

[00:06:00] **Kate:** Mmhmm. Cool. So some of the other people that we got to connect with on the webinar today, and voices that people will hear in this recording that follows, which may at some point sound like a webinar, you might hear people say, you know, "Put this in the chat box." It was super participatory. I think one of the most impactful things for me was to see the way that people in the chat were just crowdsourcing. Like when you talk about people who live with chronic illness and with disabilities being the forefront of wisdom and expertise on how to deal with health crisis moments like the one we're collectively facing right now, that was so evident in the chat of this event that we just did of just people saying, "Here's how you make sanitizer at home. Here is how to solve this problem if you don't have access to masks. What are we gonna do for encampments and people who are living on the streets who don't have access to self-quarantining in the same kind of way that we're talking about? What do you do if you're quarantined, but you're dealing with isolation," right? What is all of the wisdom that already exists in the community? People just sharing with each other and organizing each other: How are we gonna take care of each other?

So in addition to all of that happening in the background, we're gonna hear from a couple of voices in this recording. Can you tell us who we're hearing from?

JD: Sure. OK, so we had Evvie Ormon from Emergent Phoenix Consulting who led us in presencing and held down a breakout room that offered grounding practices throughout our time together. Dr. Crissaris Sarnelli, and then Elandria Williams from PeoplesHub were the primary other speakers and facilitators you'll hear.

Kate: Yeah. Super grateful to PeoplesHub for coming in and holding us in some technological infrastructure that had some disability justice considerations.

JD: Mmhmm.

Kate: And to Evvie for holding a grounding space throughout the entire call that people could actually tap out of the main group conversation and go and do some grounding

practices. That was really cool. So as we jump in, [00:08:00] we're actually gonna start by hearing from Evvie with a little bit of grounding practice to help all of us ground and come into our bodies as we talk about something that can feel a little ungrounding or a little scary, is talking about a virus spreading around the world. It's a little freaky, right? And so here we are with Evvie leading us in grounding practice.

Evvie Ormon: Hi, my name is Evvie Ormon from Emergent Phoenix Consulting. I'm currently in Salt Lake City, just so you know where I'm located. More and more research is showing, around our brain and trauma, that our bodies are our greatest source of information as far as how to heal and how to be connected to the world and to other humans. And sometimes in situations like a rapid spread of the coronavirus that's happening now for everyone, but especially for folks who are living with chronic illness, thinking and talking about it can bring up a lot of fear. And that can activate our amygdala in our brains, and we can experience that as trauma or as a trigger. So thinking about talking about things that are about our finite bodies can be frightening sometimes. And when our amygdala is lit up with fear, it overrides our prefrontal cortex, which is the part right in the front of our brains. And that part of our brain does really many important behaviors like planning, like empathy and compassion.

And for this conversation, obviously, we want those functions to be completely available as much as possible. And I say our collective nervous [00:10:00] system and our individual nervous system, because by gathering together at the same time for a shared purpose, we have already created a field, and all of our nervous systems are linked together and connected. And we are listening or reading the same words and contemplating related things. And even just taking a moment to think about that and presence that we all showed up here, and we are here to share a conversation with each other, that can start to settle our nervous systems. And I will hand it over to Crissaris to share these words while we presence.

Crissaris Sarnelli: Hello, beautiful people. Hello again. So we're in all different time zones, I believe. Some folks may be just waking up. Others may have had a whole day full of care and other work. Basically, we're coming from a lot of different experiences. So I'd like to take this moment for us to take a collective breath together. So we can go ahead and take a deep breath in. [pause] And out. [exhales, then pauses] Another deep breath in. [inhales, then pauses] And out with a sigh. [relaxed, long sigh] Now, settled into your body, as we continue breathing in and out, be sure to breathe in gratitude for yourselves for choosing this time to be here. With every breath out, let fall away, roll off all the things that will not be attended to during this time. [pause] Briefly scan from your crown to your root for any areas in your body that are asking for extra attention right now. Breathe lovingly into those places. [00:12:00] All of you is welcome here. [pause]

We'd also like to take this time to acknowledge those who have passed as a result of coronavirus, both directly and indirectly. May we honor them with our gathering and by

how we protect and care for each other and ourselves. Your grief is also welcome here. [pause] Please take another deep breath in, in gratitude for your body, mind, spirit, and all they do. And out [exhales deeply] loving energy to all the people who may be in the room with you, on your street, who live in your town, city, state, landmass, to all the people on the planet right now, to all the people who have been and all the people who will be. May we feel our loving breath connect us. [pause] In one more time. [pause] And out. [deep exhale] Thank you. [pause]

JD: Hi, everyone. Thank you for taking some time to sit with yourself with where you are right now, and to everyone who's brought us this far in our time together today. My name's JD Davids, and I'm just gonna share for a few minutes my thoughts on how we know what we know, and we know what we need. Right now is a very big part of my ritual year because it's Purim, which is a Jewish holiday that's kind of alien and about the world turning upside down and being topsy turvy. There's always something, you know, being topsy turvy. And what's been interesting, being at Purim, in a Purim ritual space as a queer living with chronic illnesses, is [00:14:00] that when the world turns upside down, maybe when it's recognized that those who know what we know and know what we need get listened to or get seen.

And so last night, I dreamed about two of my HIV activist ancestors. So I'd like to say hello to John Paul Hammond and Kiyoshi Kuromiya and talk about the knowledge they brought into my life very quickly. John Paul bringing the knowledge of what we now, I think, would call or the practice of what we now call pleasure activism with a really loud whooping call at dance parties. And Kiyoshi Kuromiya by understanding that we work wherever we are, we work in the ways that we work, and that we always can bring whatever we bring to work together on what we need. And for years and years in the HIV pandemic and particularly in the US, there was no standard of care that was put out by the, there was no central standard of care for medical care in HIV disease. So [ACT UP Philadelphia](#) did 13 editions of a Standard of Care. And we published it. It was in English and Spanish, and it was something that was two sides that people could, of a four-page document, that people could take with them to their medical providers, take with them to their appointments, and say, "Here's what I know I know. And here's what I know I need." And that has been the lesson I've taken with me since those times.

But I just wanted to ask what I'm afraid I already know the answer to: How many articles, how many mainstream news stories, how many TV reports have any of us seen in the last couple weeks or last month that have asked or talked to, featured, or quoted the real experts in what they're talking about right now? [00:16:00] How many have talked to people who live in their beds about how to live in the bed? How many people, how many reports have talked to people who live at home about how to thrive living at home? How many people have been talked to or given space and a broadcast mic to talk about what they do to stay healthy in a circumstance where the circumstances of their living situation are not under their own control? The people who have been living with a pandemic of

marginalization, disregard, or neglect for much of their lives or their whole lives are the people who have the expertise we need today, and that could help the rest of the world, yet continue to be disregarded.

I identify as a illder, which is a word I think I made up. That has to do with being an elder maybe faster than I would've been otherwise, who has learned some things by living with chronic illness. And I am [pause] always grateful for the disability justice movement and its model of crip wisdom that insists on what I'm saying now and has been bringing people together who are the leaders in living as themselves and that we collectively can demand to be regarded as the experts on what's going on today.

We're asking people, if you can, to contribute to a forum where we're continuing to collect your wisdom and experiences and also to share the resources that you've found useful or that you've created and would like to get out there and to continue to express your questions and concerns. This and the next link I'm going to tell you both use letters that stand for [Chronically Ill Leadership \[00:18:00\] for Emergent Times: CILFET, c i l f e t](#). So, the first link is bitly, which is something we use to shorten links. So, it's bit.ly/CILFETShare. C i l f e t share, s h a r e. That's bit dot ly slash c i l f e t s h a r e. We also, for those who have funds that you could contribute or know those who could, please consider making a contribution through, we have a GoFundMe up. And that's available if you go to bit.ly (b i t dot l y) slash c i l f e t funds (f u n d s). That's bit.ly/cilfetfunds.

And I'd like to give the mic back to Crissaris, who's going to be presenting some information from their perspective as a physician.

Crissaris: Hey, everyone. My name is Crissaris Sarnelli. I'm a family medicine doctor, practicing currently in Harlem, New York City. I wanted to state that I come to you not as an expert on coronavirus. For example, I'm not on any specific public health panels or committees. I come to you as a healthcare provider and a healer who has reviewed the information that we currently know about the coronavirus as I've obtained it from weekly health provider calls with the New York City Department of Health, conversations with other physicians, including infectious disease doctors. And I've also gained knowledge from my experiences caring for folks in my practice and also some of what's been circulated in the Interwebs.

So it's important to note that there's [00:20:00] a lot that we don't know about the virus, but also that what we already know helps us to care for this illness. For example, we have information about similar viruses to coronavirus, so we can use that information to help us guide this time. And it's also true that while we don't have all the answers that we would like right now, it is also true that we collectively have all that we need, just like JD said earlier. And I'm really grateful and feel very honored and privileged to be able to learn with you and to be creating spaces where we can access all that we have to help care for all of us.

So for our time together, what I'll focus, there's a lot that we could talk about. [laughs] But what I'll focus on today--and there's more information in the sheet that you'll be provided--but I'm gonna focus on the healthcare precautions that you can take, also discuss how we can care for each other depending on what symptoms we're having, and then also discuss when to seek care and how to go about doing that. OK?

So for ways to stay as healthy as possible. So right now, there's no cure for the coronavirus. And we also don't know if folks who have gotten it before can get re-infected once they've recovered from it. And although this is likely true because if it behaves as viruses like it before, then people won't be re-infected. We need to make sure that we stay as healthy as possible to prevent infection. And so some of the things that we can do. You mentioned in terms of your caring already in the chat. So pay extra attention during this time to your wellness practices. So meditation, grounding, mindfulness, stress-mediating practices, also eating as healthily as you can, movement, massage as you can as well, plant allies as we discussed earlier, vitamins as well. We know that elderberry, garlic, echinacea, [00:22:00] Vitamin D, C, zinc and Omega 3 have been linked to helping improve immune function, so these are good things to take while you're not sick. You can also take them when you are, but these are things that can help boost up the immune system.

We can also practice compassion, kindness, and care with yourself and with other people. We know that this decreases stress and improves our immune response. I know that for us, we've seen during this time a lot of being on the Internet and around, I know that in the New York City subways, we've seen it as well of people expressing racism and xenophobia. We don't need to have that going on. So it's very important that we be kind and caring to each other. And I think that during this moment, I'd like to share about the interconnectedness that we know that we have with each other and the interdependence that we're looking to create.

I saw a patient just on Thursday who worked for a Chinese warehouse and is now out of work because people aren't seeking business from that particular warehouse. And so because of that, he's also now less mobile, more sedentary, and as a result of that, has increased his blood pressure, which is something that he needs to be, that we need to make sure that we care for. And so it's way up. Obviously, stress about not having a job. And also, we know that for him when he's not moving very much, his blood pressure increases. So I know that the effects of coronavirus go past anybody having the illness or trying to prevent it. It's all of us are connected in that way. We also wanna make sure that you get to know your neighbors and organizations in your community that can help you.

[00:24:00] And now the next thing is to talk about preventing the spread of the coronavirus. So everyone's heard it: Wash your hands. [laughs] There's so many different ways. We wanna make sure that it's done often and properly with soap and water, is really the best way to do that when that's accessible. There's also hand sanitizer that you can use. There's

a craze I've seen also on the Interwebs about them being out, which is very serious. And also for people to make their own hand sanitizer. And so there's a link in the document that you have that will tell you about how to make one. And there's also an article about what you might not wanna make one because it may not be effective. So it's just important to follow the directions as best as possible. And also, if your hands are soiled visibly, you should use soap and water.

Also, you want to be able to cover your cough and your sneezes. So not with your hand, but with a tissue that you can discard, or you can cough into your elbow to help you with that. And if you are sick with a cough, fever, or other cold-like symptoms, stay home if you're able. We understand that not everyone can stay home from work. That there are jobs that don't have sick days. That there's fear of loss of income. So but for those who have that accessible or can create care networks around that, calling your work and letting them know what's going on, they can hopefully, during this time, be more lenient about letting you stay home.

You'll also want to clean and disinfect the surfaces that you're around often. So there's cleaning and disinfecting are different things. Cleaning is wiping with soap and water, and that takes away the germs from the area but [00:26:00] doesn't kill the germs. So you wanna disinfect also, when you can do that with, there's a lot of cleaning wipes. But those also might be running out with folks going out to buy them en masse. But you can also use bleach, diluted bleach or 70% alcohol or more. And there's also a link there about how to make that and how to properly disinfect. And I'll discuss more later when we talk about caring for folks that are sick. But it's important that, if there's a person that's in a room that's on their own and is ill, you don't have to disinfect that often so that you decrease the exposure to the virus.

Also, avoiding handshakes is something to do. Find new and old ways of greeting people. So you can pound and fist bump, that's OK, elbows. My aunt stopped me the other day, and she gave me her foot. So that's accessible, lower extremities, to do that. And saying hello is a way to greet. And also, I just wanted to mention that this is not spread by food. So that's not something to worry about.

Who is at higher risk? This is preparing for dealing with this virus and people with chronic illness. And people with chronic illness, if your chronic illness, are at higher risk. I wanted to alert you that as of now, there's no evidence that children are at higher risk. The majority of folks who have been affected--and the greatest numbers have been in China--and it's very largely adult. We don't have any specific information right now for pregnant people, but we do know that pregnant people experience changes in their immune system that would make them more susceptible to [00:28:00] all sorts of viral respiratory infections like COVID. We also know for sure that elderly folks and people with severe chronic illness of the heart, lung, and kidney, and those who are immunosuppressed are also twice as likely to get serious illness. We know that the majority of people who have been proven to have COVID

have had mild cases, mild to moderate cases. And those who have been severe have been folks who live with chronic illness.

Specifically for folks with diabetes, I know that there are some here. What makes folks that are living with diabetes or maybe other illnesses more susceptible to getting a severe case of it is if you are constantly hyperglycemic. So if your blood sugar is usually above 200 or your A1C, if you know that, is usually higher than 7. But if you're usually well-controlled, so your A1C's usually 7 or below or you have your sugars are usually 140, then you are likely to have the same response as folks who are not living with diabetes. I want us to take a deep breath with that. [deep inhalation and exhalation] Or maybe I just needed to take a breath. [chuckles]

We're gonna go now to the caring for ourselves and each other. So for folks, I'll start with the mild symptoms. So mild symptoms are fever, subjective, which means that you feel like you have a fever, or objective that you measure with a thermometer yourself. That's one of the primary symptoms. And also, it can be and/or cough and/or runny nose, but you don't have any trouble breathing. So these are maybe like a mild cold symptoms. The thing that you should do: If you're able to, please stay at home. Do not visit a clinic. [00:30:00] Do not visit the emergency room for these symptoms. This helps us prevent illness in others, and that exposes other folks who are ill less to these, to this illness.

And so I wanted to mention that I'm here, the flu, for example, is still rampant, and in the US since last October, we've had almost 500 million people sick and up to 50,000 deaths in the United States from the flu. So if you're ill and you're walking about, then you're still also susceptible to that illness. And I've seen many people just in the last week coming in to visit me for very, very minor cold-like symptoms, which we wouldn't test for at this time. And if that person were COVID positive, then they might be able to pass it on to someone else whose immune system wouldn't be able to recover as quickly. So please stay home.

You also want to, while you're preparing for this, is contact your healthcare provider, if you have one, to ask about help for getting your extra medication. So if you have regular medications that you get refilled, see, if you don't already have this, you should go ahead and do that 'cause I think it's helpful to ask for a 90-day supply of your medicines. This won't work if you have restrictive medications. Like certain pain medications or anxiety medications, this wouldn't be possible. But for other medications, you can do that. Also, some insurances don't allow this, but you can always ask. And then if you can't get them that way, you can also switch over or connect to a mail order system to have your medications mailed to you so you don't have to leave home to get them.

You can also get and use over-the-counter medications. [00:32:00] I know I have some patients who don't ever wanna take any medication, but these will make you feel better in addition to the plan outline that we talked about. And if you have any ideas or suggestions, you can feel free to put them in the chat. But you can take medication for congestion, and

it'll make you at lesser risk of getting an infection that you need antibiotics for. The neti pot or saline rinse washes are sometimes scary [chuckles], but they're amazing at clearing out the sinuses and help you feel better, at least for the few minutes after you do it. So I recommend that as well.

The other things to do is have household items and groceries. It's not something that you need to stock up your home. It's not.... You can always go back out or have, if you have care networks, people who can get things for you who are not ill just so that you stock up on things that you need for the day. And also, do what helps you feel good when you have a cold, right? So warm liquid: soup, tea, whatever that is for you. Staying away from things that can make you sicker like alcohol or lung irritants. Eating good food that makes you feel good, enjoying good company in person or online. There's lots of ways to connect even if we can't connect in person, just like we're doing today.

Also, it's really important to ensure that folks know that you're sick. So if you are a person who has a caregiver or multiple caregivers, they'll know that you're sick, but maybe also having a larger extended group of caregivers in case those caregivers get sick. So you can have a plan for that, and also, maybe a list of emergency contacts. [00:34:00] And if there are folks who don't have anyone at this time, you can find a list of healthcare settings or clinics that have folks that you can talk to, who may have social workers that you can connect to, who will then also tell you about organizations and things like that, that might be able to help you or visit you in your home as well. There, if you have a regular doctor, they can always have someone come to your home instead of having you come to whatever site of care you normally get.

This is the longer, the longest version is still the mild symptoms. But moderate symptoms are pretty similar. You wanna wear a mask if you're sick. And if you go outside, you wanna make sure that you're not infecting other folks. So and you wanna do that until you no longer have a cough or fever symptoms, OK? And you wanna not reuse the masks because they're already contaminated once you use them, and then you're more likely to infect other people. And so the people who are well should not use them. I just wanted to show you here. This is a 95 respirator, and some folks are buying these things, and then other folks are not able to access them. For this, you have to be fitted for that to make sure that it fits actually on your face correctly and that you're not getting air out or things in. And it's a few-minute process. So you wanna make sure you're not buying these and then using them incorrectly.

In the moderate symptoms, the thing to remember is that you just feel worse. But if you have any questions, please feel free to call your healthcare providers if you have them or any ones that are around to check in with them about your symptoms, to see if you need to come to the clinic or to the hospital or to wherever they need [00:36:00] to have you be there. And also, once you're there, they'll let you know whether or not you need to be tested for COVID, and they'll call the Department of Health to figure out what the next

steps are. And that's different for each person. So and right now, there's no commercial testing planning. There's commercial testing planning in process, but the places where you can get tested are just large healthcare facilities and regular clinics.

So now for severe symptoms, this is the most important. Severe symptoms, is the main one is trouble breathing, right? So if you feel new tightness or heaviness in your chest, you have bluish lips, in children, if their ribs are collapsing or turning blue, or they're breathing by flaring their nostrils, those are signs that there's respiratory distress. That's a sign to call 9-1-1. Also, if there's new confusion or lethargy, or you're not able to wake someone up. So they're kind of sleepy, and you go and go like this, and they just for a moment stay awake and go back, that's a reason. Or any quickly changing symptoms, so any sudden change in ability to breathe or mental status, you call 9-1-1 so that they can be transferred to the hospital as soon as possible. And you wanna tell them on that call that the symptoms that you have and that you're concerned for COVID, OK, so they can come appropriately to you.

And then prior to visiting any healthcare facility, it's good to practice calling them ahead of time with your concern so that they can be ready for you when you arrive. I know that that's hard sometimes to get through, but it's important, if you're not having severe symptoms. And once you're hospitalized, you can keep in touch with folks, tell folks what's going on.

And I feel, I know that we're short on time, but I just wanted to acknowledge that the healthcare system sucks [laughs quietly] [00:38:00] and that there's so many reasons not to trust it and not to trust healthcare providers. And I think it's really important that when you're this sick, that you still go and get care because there is lifesaving equipment and care for those times. And also, when you go to visit your clinic that you tell the providers how to care for you. Most people are heart centered, and they're also tired and drained and overwhelmed. And if you just tell them, "Hey, this is how I need you to treat me," people usually stop, slow down, and are able to care for you in the way that you need.

That's all for me. So [pause] that was a lot. So right now, I'd love for you to go ahead and breathe into your body again and ground yourself and hold what, all the things I've said. And think about what's come up for you during this time and what are specific things that you wanna do to treat your symptoms, ways to care for your mind, body, and spirit during these times.

So my name's Elandria Williams, and I'm currently, right now, I'm the executive director of PeoplesHub. And thank you, JD, for reaching out for support around the tech. And then it snowballed into where we are now. But as someone who, whoo--so I have a serious respiratory illness--and so as someone with a respiratory illness and autoimmune things and all of the things [chuckles] in the universe and has been, or have had a chronic illness my entire life. For me, and as someone who's an organizer in the world, right, in this movement work, it's been really important for me to think about what this means in our

movement culture and social justice culture, right? Not just in our families, [00:40:00] in our communities, but how do we, in our social justice movements, practice what we say we wanna preach, right? How do we actually care for each other in radical ways that most of us don't actually get?

And so I'll just say, as somebody with respiratory issues, hand sanitizer is like my death knell. [laughs] So I've spent the last, and so I just wanna acknowledge that the things that people see that are wonderful, I've been ran out of convention centers, I've been ran out of a plane, I've been ran out of everything by people's scented lotions and soaps and hand sanitizers. And so the very things that people say that we're supposed to actually use, for some of us are the very things that destroy us. And so I just wanted to name it, because I think it's one of the things we don't actually talk about a lot.

And so Crissaris already talked about not buying into the racism and oppression and the ableism. But for so many of our folks, it's just unconscious, right? So what it means to me to move my walker in and out of places, people don't even get that, right? So what it means and where we're at right now in terms of what sickness means. So when everyone's like, "Oh god, I have a cold," those of us who were always in that shape, it gets even more exacerbated. And so when you are having challenges in your life, if you actually are chronically ill or disabled, what have the traditional movement and social justice responses been to you?

So here's an example. [chuckles] So I have a friend who had a break and needed time. Instead of people saying, "Oh, let's slow down. Let's have a break moment," instead, they were like, "You just, somebody deal with her," and like, we're gonna keep moving with our day. Or, oh, you had a seizure. What we're gonna do is you're still gonna write the grant reports for me as you keep having seizures. Because the grant report is more important than you going home. Or you are actually not committed to [00:42:00] the work because you need to take a break and stay in the bed. And so that's the traditional responses I've seen over my 25 years in the movement. And so the question is, what would a different response be, right? How do we actually have more liberated spaces and better feel with mutual fear and not just ones we have to do for each other, but ones that other people do for us.

And so I'm just gonna share some things that we have done at PeoplesHub. And so one thing is that we've really put care at the center of everything. So even before, in fact, because if care's not at the center, you can't actually have the impact you want in the world. And so that literally means taking weeks off, not going, this is vacation time, but time to be. [laughs] Right? Saying, OK, how do we hold each other's needs? How do we not have meetings that last for longer than an hour and a half? I have to actually take voice breaks. And so now we've instituted like 10-minute voice breaks so that everybody gets a break. Slowing down and then asking what you can do, and allow the other person to be. Because often in this work, people assume what we can and cannot do and what we want to be able

to do. Or that we shouldn't travel and that we shouldn't do things. Instead of saying, "What actually do you want to do, and how can we support each other in that?" And so for us, it's been really important to be able to actually ask the questions, to say how do we hold each other, to say, actually, "You have to take, you need to take time off. It's not good to work until 2:00 in the morning." And to recalibrate how we hold each other in a different kind of love and care. It doesn't mean we have to all be friends all the time, but how we hold each other.

And so we would love to hear other people's strategies for how you are doing that.
[00:44:00] And what would a liberatory and transformed culture mean and be for you? For those of us that are chronically ill to get over some of the, some of us have cultural barriers to sharing and cultural barriers to looking up disease and have families that are like, "You know, you're fine," unless you can see a thing flying out your body and blood is like escaping, you don't need to go to the doctor, right? So what are all the cultural norms and values that we actually have to dismantle to really show up and love on ourselves and love on each other? And then also, how do we then say to people, "What can you do to support me," right?

So I was sharing that I have asthma attacks, and I never had written down at all what you're supposed to do when one happens. And then finally, a friend was like, "You know, it would be really helpful if you could write it down, so then I would know what to do, so that I wouldn't feel stuck and helpless." And so I'm like, OK, we're in this moment where we're getting this information. For those of us that are chronically ill, it's actually even more than the things that are on the list, right? Because if hand sanitizer actually causes me to go into anaphylactic shock, then you putting on hand sanitizer is actually not the thing I need for me. I need you to use soap and water, right? And so how do we be able to share that with people?

And then the last thing I'll just say is that I am starting a thing I've wanted to do for 20 years, which are community care clinics for movement organizers who have chronic illness. And so you'll see we're gonna do one on March 23rd and one on April the 7th. But I'm super excited to talk to other people who are dealing with the same things, so we can figure out how do we really transform our movement cultures and our organizing cultures and our communities to really hold us all the way in all of our different ways of being? And so thank you all so much for this time.

Kate: So after all that information, we're gonna close with a poem.

Crissaris: ...these are words by [Dori Midnight](#):

We are humans [00:46:00] relearning to wash our hands.
Washing our hands is an act of love
Washing our hands is an act of care

Washing our hands is an act that puts the hypervigilant body at ease
Washing our hands helps us return to ourselves by washing away what does not serve.

Wash your hands

like you are washing the only teacup left that your great grandmother carried across the ocean, like you are washing the hair of a beloved who is dying, like you are washing the feet of Grace Lee Boggs, Beyonce, Jesus, your auntie, Audre Lorde, Mary Oliver- you get the picture.

Like this water is poured from a jug your best friend just carried for three miles from the spring they had to climb a mountain to reach.

Like water is a precious resource
made from time and miracle

Wash your hands and cough into your elbow, they say.

Rest more, stay home, drink water, have some soup, they say.

To which I would add: burn some plants your ancestors burned when there was fear in the air,

Boil some aromatic leaves in a pot on your stove until your windows steam up.

Open your windows

Eat a piece of garlic every day. Tie a clove around your neck.

Breathe.

My friends, it is always true, these things.

It has already been time.

It is always true that we should move with care and intention, asking

Do you want to bump elbows instead? with everyone we meet.

It is always true that people are living with one lung, with immune systems that don't work so well, or perhaps work too hard, fighting against themselves. It is already true that people are hoarding the things that the most vulnerable need.

It is already time that we might want to fly on airplanes less and not go to work when we are sick.

It is already time that we might want to know who in our neighborhood [00:48:00] has cancer, who has a baby, who is old, with children in another state, who has extra water, who has a root cellar, who is a nurse, who has a garden full of elecampane and nettles.

It is already time that temporarily non-disabled people think about people living with chronic illness and disabled folks, that young people think about old people.

It is already time to stop using synthetic fragrances to not smell like bodies, to pretend like we are not dying. It is already time to remember that those scents make so many of us sick.

It is already time to not take it personally when someone doesn't want to hug you.
It is already time to slow down and feel how scared we are.

We are already afraid, we are already living in time of fires.

When fear arises,
and it will,
let it wash over your whole body instead of staying curled up tight in your shoulders.
If your heart tightens,
Contract
and expand.
science says: compassion strengthens the immune system
We already know that, but capitalism gives us amnesia
and tricks us into thinking it's the thing that protects us
but it's the way we hold the thing.
The way we do the thing.

Those of us who have forgotten amuletic traditions,
we turn to hoarding hand sanitizer and masks.
we find someone to blame.
we think it will help.
want to blame something?
Blame capitalism. Blame patriarchy. Blame white supremacy.

It is already time to remember to hang garlic on our doors
to dip our handkerchiefs in thyme tea
to rub salt on our feet
to pray the rosary, kiss the mezuzah, cleanse with an egg.
In the middle of the night,
when you wake up with terror in your belly,
it is time to think about stardust and geological time
redwoods and dance parties and mushrooms remediating toxic soil.
it is time
to care for one another
to pray over water
to wash away fear
every time we wash our hands

[00:50:04] Thank you.

Kate: You just heard the recording from the COVID-19 coronavirus conversation about preparedness for people living with chronic illness in the United States. An enormous thank you to my friend JD, The Cranky Queer, for initiating this, putting in an obscene amount of labor over the last week, [laughs] and bringing people together to have this conversation.

JD: Thanks. I'm personally always really fond of obscenity, but it took a lotta people to do it. I just put out the call and helped anchor some things. Thank you to you and for the *Healing Justice Podcast*, not just for this, but your role in the webinar tech and stuff. And I'd like to thank a lot of the people who are involved like Celia Alario, Daisy Becerra, Jae Berlin, Sully Carmona, Kelly McGowan, Evvie Ormon, Dr. Crissaris Sarnelli, Jenny Smith-Camejo, Kate Sorensen, Emily Szklarski, Elandria Williams of PeoplesHub, and everyone at PeoplesHub for what you're building and how you helped with this. Also, a lot of this came through folks I met and that works I answered through the Emergent Strategies Institute. So shout out to Emergent Strategies and adrienne maree brown. And also word got out and help came in through the great Radical Communicators Network, RadComms. And I'm really anchored in my purpose through the Turtle Tank School for Radical Purpose.

Kate: Mm.

JD: So I wanna thank that. And then we had some organizations that also co-sponsored: [AIDS United](#), BEAM, which is the [Black Emotional and Mental Health Collective](#). The [Counter Narrative Project](#), [Health Justice Commons](#), #MEAAction, [The Positive Women's Network of the United States](#), and the [Reunion Project](#). So thanks to everybody.

Kate: Yes. And shout out to JD mentioned Turtle Tank. They did an incredible episode about desire here on the podcast. You can go back in our catalog and find the [Turtle Tank episode](#). You can also find Episode 28 [00:52:00] with Dori Midnight, whose writing we heard Dr. Crissaris reading at the beginning of that webinar, who wrote that beautiful poem. Check out Dori Midnight's work in [Episode 28](#).

There are a lot, a lot, a lot of resources that we're sharing with you. We have articles from a lot of trusted folks, including Susan Raffo, who was on [Episode 8 of this podcast](#), including Dr. Diana Quinn out of Michigan, and including the slides and a ton of resources that were compiled during and for this webinar. And so folks can check out that whole resource library about confronting COVID-19 coronavirus in community with our justice values, fighting xenophobia, and also keeping the most vulnerable and immunocompromised members of our community safe, safe and well. And so you can find all of those resources in the show notes.

I'm really excited that y'all finally got to meet JD in this really more audio way. You have been secretly behind the scenes here on our team for years now!

JD: Yeah, I have been. Yeah, when I heard you put out the call for help and you were always talking about, oh, I'm in my collective house in Ditmas Park. I'm like, I live near Ditmas Park! And I was like, oh, I'll help. So it's really great and get to work with you in person. And to be honest, as a person living with chronic illness and disability, getting to work in person with people isn't as much a part of my life as it used to be. So that's been a great opportunity for me, and I appreciate your attentiveness to access and finding out different ways for people to help.

Kate: Mm. Thank you. Yeah. JD, y'all, was involved right at the beginning when we were doing our initial research on how to do decentralized volunteer transcription for the podcast. And that effort has really grown over the past couple years. In that vein, [00:54:00] you can find the transcript of this conversation in the show notes as well to share with folks who would have more ease of access through the written word. And JD, how can people stay in touch with The Cranky Queer?

JD: Oh, just go to The Cranky Queer or *The Cranky Queer Guide to Chronic Illness* online, and you'll find me.

BOTH: [laugh]

Kate: Awesome.

[soft ambient music returns] So for the rest of you, our website is undergoing its transition this week. You can still head to [HealingJustice.org](https://healingjustice.org) to sign up for our email list so that when our name changes on March 16th, you will still be able to find us. You'll know what to look up to find us. So join our email list at [HealingJustice.org](https://healingjustice.org). A big thank you to Zach Meyer at the COALROOM for mixing and mastering this rapid response turnaround episode. And we hope that some of the information here can support you and the people you love and miss in this wild time. So sending you a lot of love and care and robust, robust desire for the mutual aid networks that we all deserve. We are the ones who are gonna take care of each other. So hear you soon.

Transcribed by Cheryl Green 3/10/20

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