

NOW LET'S TALK! THE PODCAST

TRANSCRIPT

ROZ KAY & JIMMY CAULFIELD

Hello I'm Vanessa Corwin

And, I'm Kathleen Kaan

VC: We're here with Roz Kay and Jimmy Caulfield of New York City in Manhattan. Roz and Jimmy are COVID survivors known as long haulers. These are the people who have not fully recovered from COVID19, weeks or even months after the initial onset of their symptoms. So Roz and Jimmy, thanks for joining us today. Why don't you take us through the timeline of your COVID journey.

RK: Both of us got COVID at the same time.

JC: Around the second week in March.

RK: We both had very mild symptoms. No fever. I had a stuffy nose and head cold. I thought it was allergies because it was in early spring and everything in the park was blooming. We walk in the park every day, in Central Park, and I didn't think anything of it. And then I got chills. It morphed into getting chills, and I had bad headaches, and then stuffiness. But Again, I didn't think anything of it. Then when it ended about a week later, ten days later I noticed that I couldn't smell anything. And then I thought "that's interesting," if this was allergies or hay fever, I've never lost my sense of smell so I didn't really do anything about it. I just thought, "okay it will come back." But then I started reading all the symptoms, you know, and one of the major symptoms is losing your sense of smell and taste. Then I realized, "opps, I probably had COVID. So to this day I still don't have my sense of smell or taste. So that's my journey and then Jimmy can tell you his.

JC: Yeah, and shortly after that second week in March when we believe that both of us contracted it from a friend of mine that works in Carnegie Hall as a stage hand. And, he lives in one of the buildings in our complex, and the three of us interacted one day, and this was prior to being able to get your hands on masks easily. They were being reserved, you know, PPE for front line people, so it was hard to find an outlet where we could actually purchase the masks and we finally did. Anyway, I noticed the first thing was my GI tract. I was having all kinds of gastric distress. Sometimes it was diarrhea, other times it was like you know, constipation, sometimes in the same morning it would be mixed. To this day, except for two weeks in June, I had a remission but after those two weeks in June I still have those symptoms today. I don't want to be so graphic, but it takes up my entire morning of multiple eliminations to normalize.

KK: This is horrible that it's still happening to you so many months later. But it's interesting that the two of you have such totally different symptoms.

RK: Yeah, and you know, we each did our tests ... well my doctor didn't want me going for an antibody test until she was sure that they were accurate.

JC: And reliable.

RK: And reliable. On May 22nd I took the antibody test and it showed that I had antibodies for COVID. And then, I took another test to see if I had COVID now, you know, but no sign of COVID now. So that was the way of confirming that I did have it and I have antibodies.

JC: Yeah, and my thing is very similar. So I waited as well and ended up taking the antibody test first because her doctor called and told us that the antibody test at Quest was a good and reliable one. So we both got tested for antibodies prior to COVID test, the nasal swab. But since then I've had three nasal swabs, and all negative. But I'm positive for the antibodies. So that's kind of the timeline and the symptom line.

VC: So how did you guys feel when you got the definitive word that you did have COVID?

RK: Yeah, and I kind of felt a sense ... this might be the wrong word ... relief. At least I had an answer to why I didn't have a sense of smell or taste. And it just confirmed what I thought, so you know, so we're dealing with it, you know, as best we can but its been tough. There's been a lot of aftercare as well. I mean in my case I've been working with an ENT doctor and she sent me for an MRI. She wanted to see if anything was blocking my olfactory nerve and I went for a nose endoscopy so she could see if anything was there and nothing's up there. I mean, I guess I'm relieved but the one thing I was telling you about earlier is that it has morphed into something called Arosmia. Okay, so it went from Anosmia where you can't smell anything to Parosmia where everything smells off.

JC: Putrid.

RK: Things don't smell the way that they should smell. So like, coffee is putrid, all meats are putrid, chicken putrid, turkey. Ah, fruit, bananas, oranges, apples even sugar free Ricolas. It's all putrid. So I try to get pas the smell because I know I have to eat, you know, but there's just very few things that don't give me that sense. It's really not enjoyable. I used to love dining and you know, eating and all that and now --- coffee, I used to love the smell of coffee, getting up in the morning and having that smell --- nothing.

KK: So it's worse that whatever you can smell, smells terrible. What can you eat that you can kind of enjoy?

RK: I can eat my vegan carrot cake, which I love from bear burger. I know I'm giving them a plug but I love that and can taste that. And I can taste peanut butter, like the fresh made peanut butter you get at Whole Foods, you know, from those machines, although

they don't sell them anymore from the machines. I could taste that and some bread but for the most part most things are putrid.

JC: I'd like to just add with Roz if it's extremely sweet she has some taste to it. Extremely spicy, she can taste as well. And the third category is extremely salty. She never uses salt.

RK: I never use salt.

JC: But now

RK: I salt everything.

JC: Salting everything is a habit.

RK/JC: To have some flavor. It needs some flavor.

RK: The only positive news, and I have to take it as that, when I got my flue shot my primary care doctor, I've been working with her too on this, she said, the fact that you can smell anything at all, even if it's putrid, means that your sense of smell could be coming back because COVID attacks the nerves. It's the nerves in my olfactory system or whatever, that have been damaged by COVID. So I went from not smelling anything to now things smell putrid but at least it has a smell. So she believes it will come back – so I'm praying that that's the case.

JC: And if I could add that Roz, in her sense of investigation, you know and researching things, came across an organization in the United Kingdom that's putting forth this smell training as a way of reawakening the olfactory nerve and then making a more concrete connection with your brain interpretation coming from the olfactory nerve there. So, the smell training has been slow and plodding, but it has created some little bit of a difference. Roz could tell you a little more specific.

RK: Well you know it's like physical therapy for the nose. That's all I could compare it to. You know, they give you four essential oils that they think are very representative of smells and you put drops of these in special bottles.

JC: Amber colored jars.

RK: Amber colored jars and you put it on water color paper because that's very absorbent and then you smell for 30 seconds each scent and then you record what you're smelling, if at all.

JC: And you rate it.

RK: So I've been doing that. I was better at it at the beginning and now I've slacked off, but I'm going back to it. And sometimes I could smell these things very strongly, other times, nothing.

KK: Did you order this from the Abscent.org?

RK: Abscent.org told us about it but then I ordered all these scents and the jars from Amazon.

KK: Oh really?.

RK: Yeah, they have a whole big thing on it, a whole big section on it. So again, I mean I don't know why they chose these particular scents, I mean it's rose, eucalyptus, lemon and clove. I'm not sure why but I've been following it. And then I also got lavender, but that I can't smell at all. The one scent I don't have problems with is eucalyptus, that's so strong. So that's a good sign. Anything I can smell that smells normal, I'm taking as a good sign. But other than that it hasn't affected my quality of life as much as poor Jimmy with his gastro thing which is still going on.

JC: I've had every test in the book. I just had a colonoscopy by my GI doctor in late February 27th or 28th, and that was fine. But since then she's done an endoscopy and taken biopsied pieces of my esophagus, pieces of my duodenum and a piece of the upper GI tract.

RK: And he also had to go for an MRI.

JC: I had to go for two CAT scans, one with and one without contrast in the same session, and that was really a trying situation. But all these tests verified that there's nothing physiologically that is responsible for my symptoms. My weight loss has been dramatic. I came down from 169, where I was when I started, to 145. And they can't explain the weight loss, and you know, it robs me of energy, and none of my clothes fit anymore, things like that.

VC: Do you have an appetite, do you feeling like eating?

JC: Yes, I do. As a matter of fact, I would say my appetite has actually stepped up somewhat. Although I had to eliminate dairy in the beginning because they have to do a process where they're looking at what you eat. You keep a food diary, things that might make a difference if you eliminate them, so we've been going through that process as well for these last 7, 8 months. So it's ongoing and I'm just praying, and I'm very hopeful that it will have a final resolution.

VC: Apparently there's not a lot of research that's being done around long haulers. Is that what you're finding as well?

RK: Yeah, that exactly what were finding. And I'm finding in the case of smell and taste there's more research being done in Great Britain, in the United Kingdom, that there is in the United States. The United States are focusing on the obvious symptoms like respiratory and things like that, how COVID would have a long terms effect on those processes. But they're not really doing much about the smell, taste, the gut, you know. They're not doing much at all, at least as far as we can tell. I look at the internet practically every day.

JC: It's also new and it's all ongoing.

RK: They just can't figure it out because my doctors my ENT doctor as well as my primary care, they said they've had patients that got their smell and taste back within weeks and then there's just a very few that haven't gotten it back at all. Which is me. So they don't know why and they don't have a clue.

KK: I met this woman who also had COVID and she's got all the antibodies but she said originally she couldn't taste or smell but that it did come back. What she feels is this incredible fatigue. And are you feeling that at all? Or are you just feeling like yourself.

RK: No. As a matter of fact, it's weird, no. I don't feel any other symptoms, you know, I'm not tired. I get headaches but I always had headaches, I was always subject to headaches, but other than that, man, nothing. No, I have a lot of energy; I'm fine, knock on wood so it's just this.

JC: And I feel that I fatigue very easily now. It's not a constant ongoing but it doesn't take much activity for me to feel fatigue and that's never been me.

VC: When you guys first became sick was there any contact tracing going on? Did you take it upon yourselves to notify people? How did you proceed with that?

RK: Actually no, there was no contact tracing but we knew. We did our own. And we figured out that his friend, we knew like the day that we spoke to his friend was in the lobby of his building and his friend wasn't feeling good.

JC: We didn't have masks yet.

RK: We didn't have masks so we figured it had to be from his friend.

JC: And he tested positive for antibodies just like we did long before he had the COVID test. I'm not even sure if he had the COVID test after that. I have to be honest, but he did have the antibodies and he told us right away. So we should be on guard.

RK: And then Kat, I told you because we had been together in the beginning of March. We've been isolating all this time, we haven't even seen our families.

JC: Except on Zoom.

RC: Except on Zoom. We've been isolating. The only thing we do, we walk in the park every day when we can, when the weather is good. We wear masks now, we're very conscious of that. So we did our own contact tracing. Basically that's it.

KK: Have you found from the internet a group of people that have gone through what you're going through because you can relate to them.

RK: I think I mentioned this organization [Abscent.org](https://www.abscent.org) from the United Kingdom. They have a facebook page and so I joined the group. And their experiences are exactly like mine and some are even worse. Now, there's something even worse called "phantom." There's parosmia, phantosmia, something like that. That is when you're smelling something that isn't there.

JC: Isn't really there.

RK: So I haven't had that thank God, but everybody is expressing what tastes and what smells really bad to them. And there is a sense of like damn, when is this going to end? Some people when they get their smell back, they'll post that and give us words of encouragement like "hang in there."

JC: Which is very useful.

RK: But we haven't found anyone who has the gastro. I'm sure there's one out there but we haven't found it.

JC: We haven't found a group that does but we read a lot of research that something like 32 or 33 percent of people positive for COVID have GI issues long term issues.

VC: What advice do you have for fellow long haulers out there? And what resources do you recommend that they check out?

RK: Well fellow long haulers, it depends on what part of your body COVID has ...

JC: Yeah, what are your symptoms and what are they related to?

RK: And, try to find groups that you can join on Facebook specific to whatever symptoms you're experiencing. I find that these groups are reporting on the latest research and they'll post links to articles and case histories and stuff and maybe some potential drugs that in the works, treatments, so that's where I'm finding of my information. So that's what I recommend to long haulers, is to just keep reading trusted websites and join Facebook groups and keep abreast of the situation and, of our course, work with your doctors. I mean for me working with my ENT doctor, you know she's using my case as research because they don't know.

JC: She's building her own data base from her patient load.

RK: Yeah, and the more that the doctors do that they can share information, maybe the sooner they'll come up with some kind of treatment. And, the same thing for GI. Jimmy's working with his GI doctor and that what I would recommend. Just really go out there to the Internet.

VC: That's great. Roz you mentioned perhaps, does Mount Sinai have a program?

RK: Yes. In fact, I haven't been there. I saw on their website that they have an [after-COVID-care unit](#) they've set up. But the last I checked they haven't done anything about smell, taste or even GI. See that's what I'm saying, they're focusing on the obvious symptoms of COVID, like the respiratory.

JC: The deadliest.

RK: Yeah, the deadliest parts. So they're tracking cases with people who either were on ventilators, running high fevers, you know, like what are the after effects from that.

JC: Cardiac issues.

RK: Yeah, so they really aren't focusing on loss of sense and smell and GI issues. Maybe they are now, but the last I checked, about a month ago, they hadn't done it. But that would be another resource for people, if they're still suffering from other symptoms, to look at that.

VC: And this would be in the New York area, correct?

RK: Yeah, Mount Sinai.

VC: Well guys, thank you so much for sharing your journey with us.

JC: You're welcome. Thank you for giving us a forum to express these concerns because quite often keeping it all to yourself, it just builds your anxiety if you're holding in, and to be able to speak about it openly to people who are open and are understanding of the situation helps the both of us in return.