

You First Podcast Episode 68: Long Covid & Grilled Cheese

Maddie Crowley (00:00:00):

You're listening to You First: the Disability Rights Florida Podcast. On this episode, we talk about long COVID and somehow how grilled cheese connects with that.

(00:00:09):

Hey everyone. I'm Maddie.

Keith Casebonne (00:00:29):

And I'm Keith. And we are the hosts of You First.

Maddie Crowley (00:00:33):

And as you all may have noticed, depending on how close you follow the podcast, typically we put episodes out every two weeks, but this is now three weeks after our previous episode, and we're going to do a little bit of a different episode today and discuss a variety of things. They might seem a little random at first, but for a couple of reasons. We had to push back releasing an episode last week and got on a bit of a disjointed schedule, and we kind of are just going to try something different as something a little more casual.

(00:01:14):

Keith and I are just going to talk for a bit and have a different flow today, and then we will hopefully get back to our standard episode release in a couple of weeks and the weeks thereafter with some of our lovely guests we have set up. But anyways, Keith, do you want to talk a little bit about our episode today?

Keith Casebonne (00:01:38):

For sure. So as Maddie mentioned, it's just the two of us, no guests, but we're just going to chat a little bit. And so one of the reasons why, as Maddie mentioned, we're off a week is unfortunately Maddie's had a flare up related to long COVID, and so we thought this would be a good opportunity to talk a little bit about long COVID. It's been a while since we've talked about COVID as a topic on the podcast. And long COVID though... COVID itself is

still real. You can define a pandemic or not a pandemic, that's up to you, but it's still there. It's still out there.

(00:02:14):

And long COVID is a real thing that unfortunately a lot of people including Maddie are dealing with on a regular basis. So we are going to chat a little bit about that. And related to that, or unrelated to that, however you want to look at it, there's this newsletter, we'll link to it. It's called Pod Access. It is a newsletter specifically about deaf and disabled led podcasts that are out there. And a couple of months ago, they put out a challenge, if you will, or a creative, I don't know, creative prompt to throw in something about grilled cheese in your episodes. And hey, we're down with that here on You First, so somehow we're going to work that in, right?

Maddie Crowley (00:02:59):

We're going to work at it. And honestly, the more we talked about it seems silly that those things are seemingly so distant of topics, but they really do connect and I promise it will make sense at the end how long COVID and grilled cheese overlap. But well thank you for that kind of background and introduction. So I can talk a little bit about just my experience with long COVID and we can talk about long COVID broadly and the current presence of COVID and COVID mitigation measures and COVID and long COVID's impact on the disability community.

(00:03:36):

Those who identify with the term disability or not, those who are immunocompromised, those who have other marginalized identities, et cetera, et cetera. And some of the current things going on in relation to COVID and masking, and just have a conversation about that. And then we'll pivot into how this all connects to grilled cheese at the end as we talk about one of my favorite sick meals, my long COVID meals. Something that's super easy to make and accessible when you're not feeling too good.

Keith Casebonne (00:04:14):

It will make sense. We haven't gotten there yet, but I'm sure by the time we do, it'll all make sense. Right, exactly.

Maddie Crowley (00:04:21):

We're telling ourselves that.

Keith Casebonne (00:04:23):

Exactly.

Maddie Crowley (00:04:24):

Please stick with us. No.

Keith Casebonne (00:04:25):

Exactly.

Maddie Crowley (00:04:25):

So unfortunately, I'm sure thousands, if not millions of Americans, let alone millions of people around the world impacted by long COVID. I have long COVID and have been dealing with it for... What month is it? Still June, that's wild. Memory is an issue in long COVID. So essentially to my knowledge, I've only had COVID once, which is again, only to my knowledge that I've actively tested positive on a COVID test, and that was back in 2022. And throughout the whole pandemic, I have tried to be really safe as I have a variety of other "comorbidities" or other conditions that impact how badly my body, my immune system and other things will deal with having COVID and subsequent long COVID.

(00:05:30):

So like I said, I had COVID back in 2022, and as you all know, it is now 2024. So I got it over two years ago and later in that year I started having heart issues and I'll just say I have a form of muscular dystrophy along with some other conditions and heart issues has never been an issue with my health. I've always had really great heart health and no issues. And then suddenly I started having tachycardia, which essentially means a really high heart rate. That was six months after I had COVID. And in the time that I was actively dealing with COVID and active infection, whatever. I wasn't experiencing any heart issues.

(00:06:14):

I recovered after about a month and a half or so after getting COVID. I was okay, no other issues, et cetera. So my infection was in May, and then around fall, winter of that year, I started having these heart issues. And at first it was really confusing because it was seemingly out of nowhere that I had really high heart rate. For example, 120, 130, just sitting down, waking up in the morning, that would just be my baseline, which is very exhausting to have your heart rate be beating that fast a minute because a normal is under

a hundred or around 90 and even lower than that. So suddenly having this high heart rate was very unusual to me.

(00:07:07):

A whole host of diagnostic things happened, doing different tests, wearing a heart monitor, wearing different pulse... Things that recognize my pulse and spikes in my pulse. So I had an Apple Watch, I had a different monitor to record EKGs constantly that I could send to my doctors, and everything came back completely normal. I just had a high heart rate. I went through all of my various medications, stop different medications. So I was on Concerta, which is an ADHD medication that helps with focus. Got off that because it could be possible that ADHD medication can-

Keith Casebonne (00:07:47):

Possible side effects.

Maddie Crowley (00:07:48):

Elevate your heart rate along with other ADHD medications. That happens more frequently too. I had been on Adderall before and had actually gotten off of it because of that and was doing fine on Concerta, but was like, "Let's rule that out. There's no reason to hold onto that just in case that is the case." And then it got to the point where it was still bad that I had to get testing because I thought I had a pulmonary embolism and I was going to the ER. It was a whole thing. And then again, I consistently tested negative for all of those issues and was fine, but any exercise I was doing, I was spiking into the 160s of my heart rate, almost passing out at different points of the day.

(00:08:31):

And it was a time, still is a time as I'm still dealing with it, but it's a little bit better now. But it was all this mystery thing. So eventually it was like doctors didn't really know what was going on, just said, "Let's wait and see. At this point, you're not in any inherent danger as it's not a pulmonary embolism. For whatever reason, this is happening with your body." And thankfully, my sister, shout to my sister if she listens to this, she is really well-informed about COVID and long COVID, and was actually the person for our public health department to track COVID numbers and related information.

(00:09:14):

So she was a super great person to have on my side and was one of the very early people in this whole storyline to say, "I think it's possible you have long COVID."

Keith Casebonne (00:09:28):

So she's the first one to bring it up, not a doctor or a healthcare professional or... Interesting.

Maddie Crowley (00:09:33):

Actually, it's frustrating. Well, I'm grateful for my sister, obviously, but at this time, two years ago, mind you, this is back in 2022, this was about a year or so after people finally got vaccines. And we are just starting to understand that wow, there really are real long-term impacts of COVID. But those people and the real long-term impacts were relatively new scientifically. To the point that there wasn't a full understanding of how this would be understood medically or discussed medically or thought of as a potential diagnostic kind of, I guess, diagnosis for what I was experiencing because I wasn't having any of these other "long COVID symptoms" beyond the heart rate.

(00:10:31):

And unfortunately, not only that, but this is also at the same time that because we have these vaccines and there's a lot of making COVID and masking and all these things very political. A lot of healthcare professionals and doctors, not only were no longer masking, but no longer thinking of COVID as an issue or really validating when I brought up to the point of saying, "Hey, do you think this could be long? I had COVID, is it possible?" And I got brushed off many, many, many times by a lot of doctors that unfortunately I trust and have had a great relationship throughout months to years of my life.

Keith Casebonne (00:11:19):

That's a shame.

Maddie Crowley (00:11:19):

And unfortunately, that's still an ongoing theme, not just for me, but for a lot of people that are suddenly, "Why am I sick? Why is everybody still sick? It's summer. Why is there a summer flu? It's the long COVID or it's COVID." But people don't have the tools to name what's happening and how rapidly COVID continues to evolve as a virus. Anyways, we can talk about that later. But as I went about my life, I was just chilling. And for about a year or so, I was dealing with the high heart rate, still trying to investigate why, I underwent a move,

I got reestablished in a new healthcare system and larger hospital system and I brought it up and continued to do tests and showed people like, "Hey, this is an issue."

(00:12:19):

But they're like, "You're not at any imminent danger right now with where it's at and everything else seems fine, so there's not really anything we can do." Which even now is true. So fast-forward to the beginning of this year in January of 2024. I went on a brief trip and I traveled across the country one day, did a bunch of testing for an unrelated medical thing, and then came back the day or so after that, and it was within the next day or two that I suddenly was basically completely unable do anything.

Keith Casebonne (00:13:09):

Total exhaustion, no energy, no...?

Maddie Crowley (00:13:16):

That's a good question. So full physical exhaustion, mental exhaustion. I had a whole host of symptoms just out of nowhere, and this kind of became the beginning of what I now coin as these long COVID flareups, which is something that is really tricky about long COVID people can have COVID once me two years ago, and then randomly, for whatever reason, the virus or underlying condition just gets triggered and it then manifests into what we now know as long COVID. So full total body exhaustion. I couldn't get out of bed. I couldn't really move. I had very feverish symptoms.

(00:14:06):

Any work that I tried to do or any activity I tried to do, I would start sweating. I had tinnitus, I had body aches, I had tons of GI issues, and it was just seemingly out of nowhere. Yes, as someone with a variety preexisting conditions, like I said, someone with muscular dystrophy, that level of travel is pretty strenuous on my body. Something like a really quick two or three-day trip can be really exhausting for me, and I have gotten sick from things like that in the past, but this was beyond anything I had ever experienced, and it lasted three or four weeks. That level of just incapacity. So that was-

Keith Casebonne (00:14:52):

That's a long time for something like that. That is a ridiculously long time.

Maddie Crowley (00:14:55):

And it was then that I came to realize that, "Oh wow, this... Do I have... What am I dealing with here?" Because it was seemingly out of nowhere, right? Do I have mono? Do I have some kind of Lyme disease? Do I have all of these different things? Everything I did, I ended up testing negative. The only thing that remained was again, my sister, what she told me months or almost a year prior was it's probably long COVID. And so that was the beginning of what has become quite a not so fun year. I have since had, I can't really remember, three or four episodes, but they weren't to that extent. That was the big flare up where it lasted a while.

(00:15:45):

But we started the episode discussing, I was out just recently because I got sick for 10 days to 14 days. I didn't have COVID. I tested negative for COVID. I didn't actively have COVID. And again, I was having those same experiences, just full body exhaustion. And what has developed for me personally is more than the physical bodily exhaustion. It's more of cognitive exhaustion. So how my long COVID manifests is that I'm quite literally unable to work. And thankfully I work for a disability rights organization that not only understands disability and is more flexible than your average organization to empathize and understand what having a variety of disabilities means.

(00:16:45):

I end up missing essentially two weeks of work because of that. And that's why this podcast is happening right now, the way it is. And we can get into a little bit of how long COVID can manifest and all of that stuff, but I think it's really important to emphasize that even for me, I don't have any coughing. I don't have any sore throat. I don't have any of what your typical active COVID infection symptoms aren't the same as a long COVID symptom. And I think that's really important to say because I think that's one of the biggest misconceptions about COVID and long COVID is that a lot of people, yes, they do have the shortness of breath, I have that, but not everybody experiences that.

(00:17:39):

And that's why I really wanted to highlight that how mine currently manifests is more of that cognitive side of things because of how my brain and cognition and overall nervous system has been impacted by COVID, is more of how I've grown to understand long COVID for me personally. Anyways, that was a long backstory, but think it was helpful to explain.

Keith Casebonne (00:18:06):

For sure, for sure. So it was earlier... Well, I'm assuming of course, have you had a formal diagnosis of long COVID finally? A doctor has officially said that this appears to be long COVID.

Maddie Crowley (00:18:19):

So finally, and I will say that took a lot of work as well, unfortunately. So I'm really grateful to live next to a large research based university that has a really great long COVID program. That I was able to get on a waiting list to get a part of their long COVID therapy programs and stuff. But that only started a month ago. I was on the wait list for about three or four months just to get an appointment for a doctor to assess me. And essentially he was like, "Yeah, you have it all. It sounds like a very classic case of long COVID." And I mentioned I can just speak a little bit to my symptoms and we can talk a little bit about the things that I don't experience also are considered long COVID symptoms from the research done through the CDC and other universities that are studying this.

(00:19:13):

Like I mentioned, but again, I'll just repeat, the bodily fatigue, the cognitive fatigue, the tinnitus. I also have issues sleeping. I have really bad night sweats, which is more annoying than anything. Again, I missed this before, but it's so funny, the memory issues. It's funny that I missed it because I forget that's part of my symptoms is the memory issues. A lot of my short-term memory and active ability to pay attention, anything related to my cognition has been really impacted. And I've since started some testing related to that and had some previous testing related to that when I got diagnosed with ADHD.

(00:19:56):

And I was able actually to see how long COVID impacted me because I now have subsequent testing to compare it to how my ability to pay attention and use my working memory has been extremely diminished. And we can talk about some resources related to how you can help with that even if you don't have long COVID. Anyways. I think I said tinnitus, but there's a whole host of things that may feel like indicators of something else. But what's really important to say is long COVID is an inflammatory multisystemic, so body systems, condition that we still are trying to understand.

(00:20:41):

But as my... I still have the high heart rate and shortness of breath related to that. And I just think it's important to say that people are still coming to understand what long COVID is.

Just a week or two ago when I was having my flare up, I started having these really intense, almost like when you have a fever, you get those shakes, what are those called? Not tremors, but when you have the flu, your body gets shaky, like shivers. I would get shivers out of nowhere and I text my sister and say, "Hello, are shivers a long COVID symptom?" And she's like, "I mean, I don't know, but probably because everything is ending up being impacted by this multi-systemic thing."

(00:21:34):

So I know we wanted to pull up some data and other kind of symptoms. I know you probably have that pulled up, so I'll stop yapping.

Keith Casebonne (00:21:45):

No, you're good. No, that's fine. The story is fascinating and it's crucial to what we want to talk about here. And so getting a deep understanding of the process of what you've gone through, which is I'm sure... Well, obviously it's unique to you in some respects, but I'm sure there are hundreds of thousands of people, if not millions, that mirror this path of unknown, what is going on, unexplained symptoms coming here and there. And then over time, months, years, even later from having had COVID, finally maybe connecting the dots and realizing that, "Oh, this actually could be long COVID." And even coming to that point still, like you said, you'd have to get a doctor to see that and understand, make that leap because there is no test for this.

(00:22:32):

So for a doctor to ultimately say it looks like long COVID. To me, it seems like the kind of thing that you rule out almost everything else, and you're left with, "Well, there's all these symptoms we can't figure out. There's no reason why you would have these that you normally have them. So therefore this looks like long COVID." But you mentioned that there are so many, and the CDC recognizes more than 200 long COVID symptoms that have been identified. Over 200. Now, not everyone has all 200, but 200 have been identified. Now the most common ones, and you've mentioned a lot of this, fatigue, brain fog, something called post exertional malaise or PEM.

(00:23:15):

So of course you do something, like you said, you travel and you come back and you're not just whipped from a trip and need a day of rest and then you're back at it. No, you are down for the count for, like you mentioned at the beginning, three, four weeks. So that's a huge...

I think even malaise is an understatement word for it. But some of the things that they mentioned here, this will be some overlap of what you've said, but tiredness or fatigue that interferes with daily life. So again, that's clear that it's not just being tired. It really does interfere with your ability to do your daily activities.

(00:23:51):

Symptoms that get worse after physical or mental effort, fever. Then this is where it gets off the most common list. But as you mentioned, fast beating or pounding heart, also known as heart palpitations, difficulty breathing, shortness of breath. You can have coughing, you don't, but you could have coughing. But then there's the brain fog, headaches, sleep problems, lightheadedness or dizziness when you stand up. Some people get that pins and needles feeling in their extremities. You can have a change in smell or taste, which is I guess a regular COVID symptom too. It can lead to depression, it can lead to anxiety.

(00:24:31):

I think you mentioned some digestive symptoms. There's things like constipation or diarrhea, stomach pain, joint pain. You can have rashes.

Maddie Crowley (00:24:39):

As we're talking. I'm like, "Oh, I guess I do have a joint pain too."

Keith Casebonne (00:24:45):

It can even affect changes in a woman's menstrual cycles. This is the level... It's amazing how systemic this is.

Maddie Crowley (00:24:56):

For sure, and that's why I really wanted to highlight the fact that it is like this multisystemic inflammatory condition where this virus, how it's currently understood, and I apologize, please, we are not doctors. I do not have a scientific background. All of this is my own. I'll just say to clarify, this is my own experience and what I have learned. Please do not take my experience and what I'm saying as absolute truth. Please do your own research and talk to your doctors. But just in my own understanding of the condition and things, it's like COVID can live on a basement level in your body and kind of always be there.

(00:25:38):

So for example, if you've had mono, the mono virus and other viruses can live in your body even after you've had it. It's not necessarily that you're going to get it again or anything like that. But that's the case to my understanding with COVID and having long COVID is that these... Especially for folks who've had multiple repeat infections of COVID, and when I say that is when you've had COVID multiple times, is that the virus doesn't just leave your body after you have COVID and you're perfectly fine and you had COVID and it's gone. This virus lives in your body. There's research to show that it can live and destruct your bone marrow and things like that.

(00:26:27):

It's really insidious stuff as how it can impact each level of your body, and not only from a cellular level, but to this whole systemic way we're understanding how it's impacting not just your cardiovascular systems like your heart or your muscular system. So your muscles or your neuromuscular, your nervous system impacts how your muscles work. It impacts every single one of these bodily systems. And that's why it's such a hard disease to not only diagnose, but understand is it's not just, "Oh, that person still has a cough," or, "Oh, that person still has shortness of breath."

(00:27:09):

As we understand COVID to mainly impact people when they are actively infectious or even recovering from an infection. It impacts you beyond that. And I think that's why we wanted to list some of those symptoms after telling my story, is to really highlight that it has this long-lasting impact on things beyond how people understand COVID itself as a present infection.

Keith Casebonne (00:27:41):

So true. And again, I'll back up the same thing that you said. I'm not a doctor or a professional in this either obviously. If you ever thought we were, I don't know who you think you've been listening to in this podcast, but we're using some references from the CDC and some other sites to get this information, and we're going to have links so you can see the same stuff we're using as reference. But one thing I wanted to mention off of one of the pages on the CDC's website, you mentioned your inability to work as much as you have been able to in the past.

(00:28:08):

And the interesting point here, there are some estimates that suggest that more than a million adults in the United States alone are out of work at any given time due to long COVID.

Maddie Crowley (00:28:20):

And under count too.

Keith Casebonne (00:28:22):

That's huge. Right. Because it what's reported, and I'm sure there's many that are out and don't even realize that might be why, but it can result in reduced ability to work full time. This also can mean increased healthcare costs, but for some people it might mean food and housing hardships, like financial hardship because they can't work. There's a link to resources available for both employees and employers to better understand how it can affect them and their work. So if you're someone dealing with that, we'll have links to that as well.

Maddie Crowley (00:28:54):

And I want to name too how I started discussing that I was out of work and I'm incredibly grateful to work for a disability rights organization. I work fully remote. I have the opportunity to make my own hours per se. I should be available and reply to emails within a timely basis. But other than that, if I'm out sick or need to take time off, I'm given a ton of grace and I know that. I am unfortunately the very, very, very less likely scenario for so many people have to quit their jobs and just not be able to work or fight really hard for work from home accommodations or hybrid accommodations if they even can work.

(00:29:56):

So definitely we'll link to those resources along with any other resources we talk about or any other resources we find along the way, we'll link to those. Because unfortunately it still is such a under discussed condition. But also just like you mentioned, it's not super well understood in a workforce working... What's the word? Context.

Keith Casebonne (00:30:23):

Sort an employment setting or a context, right?

Maddie Crowley (00:30:28):

I will say I am also, again incredibly fortunate that not only my sister is actively learning constant COVID information, she's reading all of the research studies, she's the person that's calculating the data, seeing the data firsthand as far as spikes in the numbers, how people are getting infected with COVID, et cetera. That has been a crucial aspect to my wellness and how I have since been able to process and seek treatment related to COVID. And I know that's not the case for so many people. And again, I've also been super-duper incredibly fortunate to have access to a long COVID clinic as they are not universal at different hospitals, even at different universities.

(00:31:18):

And so just with that, again, this is not medical advice, but I'll share briefly a couple of things that I've learned in case that you are dealing with this. Long COVID does not get better without changing anything in your life. And unfortunately, I have had to turn down different speaking engagements. Keith and I were just talking, I'm a fellow for the Coelho Center for Disability Policy and Law, and they have a conference in California in July. I'm not able to go in person, I'm joining remote, which is obviously great that they have a remote option, but these are choices that I have to make in order to save my health and make sure that I'm not having these active flareups and further making the condition worse or disabling my body more.

(00:32:07):

So I just want to say that part of what I've learned is that pacing and rest and not straining your body more than what is absolutely necessary is the key to dealing with long COVID. Because I know people are not able to see a long COVID specialist or get into a research program. And I know that's incredibly frustrating, but that's the case. So just like for me, pretty much my capacity right now is if I'm able to work at a certain week, I basically work and I eat and I sleep and I rest on the weekends. And that's all I have the capacity to do right now. And being really real with yourself about pacing, taking breaks while you're working.

(00:33:00):

For me, this is really hard trying to do, focusing on one thing at a time, not multitasking because that's very cognitively draining. These little tricks that you can implement into your life to ensure that you're not overwhelming yourself and over exerting your body is what's going to help a lot of people the most. Because like we mentioned, there's not a lot of treatment. There's not a lot of doctors, and I'll say it, there's no specific treatment to...

There's no cure for long COVID. A lot of what people are saying online is that time and pacing is what's going to help, and that's what's been helping me.

(00:33:40):

So I just wanted to put that out there that if you see that online where folks are saying pace yourself, take your energy, your sleep, all these things super seriously, it's because that's true. There isn't some secret medication or cure behind closed doors at a long COVID clinic. That is actually what is the current treatment protocol that I was given even at this long COVID center that I go to. So I just wanted to make sure that I said that and that was well understood.

Keith Casebonne (00:34:15):

And of course, if you haven't figured it out by now, when you're hearing all this and things we're talking about, this is a disabling condition. And so you may be someone that has not identified as having a disability and you've gotten COVID. And at some point down the line, again, this could be months or years later, you start having long COVID symptoms and they get to the point where they do affect your ability to do certain things. And it becomes, again, like I said, a "disabling condition". And so we thought it was important to point that out that long COVID can be considered a disability under the ADA, the American Disabilities Act.

(00:35:03):

And so as we talk about some of the challenges-

Maddie Crowley (00:35:08):

It's really real

Keith Casebonne (00:35:10):

It's really real. If you have long COVID and you're dealing with a lot of these things and perhaps missing work or unable to provide your own self-care or things like that, know that you may have options as far as rights afforded under the ADA or other healthcare, things like that, access to maybe different forms of healthcare you might not have had before, things like that. So those are things worth investigating as well. And that's I think, an important thing, especially for the nature of this podcast and what we generally talk about, that this is a disability, this is a real thing.

(00:35:50):

So another thing I know we want to talk about a little bit, especially because I think there's some timeliness right now as far as some political moves that are going on across the country, we want to talk about masking. And I know that you're aware of a couple of things that are going on that when we talked beforehand, before we started recording, I was not aware of. So what are some of the things going on around the country involving masking and, I don't know, the politicizing of disease, unfortunately.

Maddie Crowley (00:36:15):

For sure. So before we get into that, I want to say that although currently there's no "mask mandates" or even recommendations that you really should be masking in all of these different social settings, medical settings, what have you. On the CDC's website, despite the CDC reducing masking recommendations and precautions, they say that the way to protect yourself from getting long COVID is to wear a well fitting N95, KN95 or otherwise approved high quality mask. Essentially saying, just so we're clear, that the way to not get long COVID is to not get COVID and to wear a mask despite them saying that masks are optional or whatever.

(00:37:11):

So we're starting to get into the politicization.

Keith Casebonne (00:37:14):

I got to cut in real quick because you just said the most straightforward possible thing that anyone... You don't get long COVID if you don't get COVID. And to not get COVID, you have to wear a mask. Really? Sorry, it's so blatantly obvious, but yet the fact that some people don't see it that way is... Well, it ticks us off. Carry on. Carry on.

Maddie Crowley (00:37:41):

And again, for those who are listening, that unfortunately, some of this may be new information for a lot of folks because there has been a ton of mis- and disinformation out there. COVID is still very much a viral disease that only travels through the air. Through air that circulates in a building, that circulates in your apartment, that even you can get it outside if you're in denser populated areas because of the shared air interrelated with people. So the only way you can mitigate that is to protect how COVID gets into your body through the air.

(00:38:25):

So things like bringing hand sanitizer as the only mitigating measure is not effective because it doesn't transfer via droplet, it transfers through the air. I just want to make that clear. I do not have to be a scientist or a doctor to say that. It is very, very... The basic understanding of COVID that we've had since 2020 has not changed. Therefore, the basic precautions you can do for yourself and others is to protect yourself with a mask and with air filters. I have air filters around my house. You can make makeshift ones with fans and HEPA filters or other air filters to clean your air. And that's the only way you can protect yourself and others. Go ahead.

Keith Casebonne (00:39:14):

And I know a lot of people are probably thinking right now as they're listening, "Well, we have a vaccine, right? What about vaccines? You could just get vaccinated."

Maddie Crowley (00:39:21):

Vaccines are important too.

Keith Casebonne (00:39:22):

Yes, vaccines are huge, right? But they're not... With few exceptions, vaccines are not automatically a hundred percent. We've had some vaccines for years and years that we know pretty much are a hundred percent. The COVID vaccine, while very effective and most definitely anyone who is in the healthcare profession, anyone who knows anything would recommend, of course you should get the vaccine. It is not a silver bullet. It will not automatically mean you'll never get COVID. It'll reduce your risk a lot. Sure. But-

Maddie Crowley (00:39:55):

A very life-threatening COVID. Right?

Keith Casebonne (00:39:58):

Exactly. Right. And that's the thing too, is that-

Maddie Crowley (00:40:00):

And you can still get COVID, even if you've gotten-

Keith Casebonne (00:40:04):

Correct. It just might not be as bad. It won't be as strong-

Maddie Crowley (00:40:06):

May not be.

Keith Casebonne (00:40:08):

It's not, you're right. There's no guarantee. Right? It may not be.

Maddie Crowley (00:40:11):

And I'll say that is also because around the time that we introduced these vaccines, it was really imperative that a certain amount of the population, a majority of the population got vaccinated because then people... So how this virus works, again for folks who this may be new information, and that's totally valid. How the virus works is that the virus mutates over time. So the COVID that we have right now is not the same COVID that we had in 2020. It mutated, I think, over a hundred times.

Keith Casebonne (00:40:48):

I was going to say quite a few times.

Maddie Crowley (00:40:51):

Someone correct me if I'm wrong, please do not quote me on that. But it's mutated many different ways, and it's because of people not getting the vaccine at the high enough rate. The COVID we have now has become resistant to that, how the vaccine currently operates in your body. So originally, say the little virus had things on the outside that looked like circles. The vaccine would protect from you getting the virus that had the little circles on the outside as a very basic understanding of virus. But now that vaccine that still only protects from the little circles is now dealing with the virus that has squares on the outside.

(00:41:40):

And it doesn't necessarily protect you in the same way that it does. And in the news now, pharmaceutical companies are developing a new and updated COVID vaccine, and some people are now getting boosters, et cetera. So they're continuing to develop it to be resistant to or to be effective against the new viruses. But that's the point of what we're talking about. To get both the vaccine and to wear a mask, you're going to be the safest against the continuing to evolve virus, if that makes sense.

Keith Casebonne (00:42:14):

Exactly. Because even... Yes, there's updated vaccines as you said, but while they're building the new vaccine, well the virus is mutating.

Maddie Crowley (00:42:24):

It's going to continue to...

Keith Casebonne (00:42:24):

So by the time that vaccine comes out, there's a mutated virus. Now, maybe it's not massively mutated, mutations vary, but the point is it is still a different virus out there. And so again, if we're always playing catch up, we're never going to catch up. And it's because of a lot of these masking problems. But it's because a lot of these masking challenges that have been put upon us that has made that... If we had all masked better in the beginning, quite honestly, we could have cut down a lot.

(00:43:00):

If everyone had gotten the vaccine in a more timely manner we may not be in the position we're in right now, but unfortunately there were a lot of political factors that made that challenging. And there's some new political factors that are making that challenging around the corner.

Maddie Crowley (00:43:18):

As you started with this whole segment. And then I started talking about vaccines work. And again, please, I am not a science person, so please...

Keith Casebonne (00:43:29):

Same.

Maddie Crowley (00:43:31):

Continue to seek out, there's tons of really great creators and doctors that are creating really plain, accessible, easy language understanding of viruses and how COVID works and stuff. And we'll link that so you can further educate yourself about how that works. But what we're talking about with masking, so like we said, the way to protect yourself from long COVID, a long time or lifetime disabling condition is to not get COVID. So that means taking precautions to not get COVID. To the best of your ability wearing a mask, cleaning the air you're in, et cetera. But there are current proposals to ban masks across the country.

(00:44:14):

So North Carolina currently, there is a bill that was passed by the Congress there. So they have a majority Congress that doesn't match the political party of the governor of North Carolina, and they proposed a mask ban in North Carolina. The governor vetoed it, but because they have a majority in otherwise other parts of the government, they could easily just overturn it and pass the mask ban there. In New York City, the governor is trying to ban masking on all public transportation because unfortunately, a lot of the messaging in connection to other developing and ongoing political things in our country with protests and things that people wear masks.

(00:45:02):

They're connecting masking to criminality, essentially equating people who wear masks as people who are trying to hide their face to evade the police, et cetera. So in New York, to my understanding, the current discussion is that if you're positive for COVID, if you're trying to keep other people around you safe and not spread COVID, yes, you can wear a mask, but that's not how people don't get COVID or don't get long COVID, is that a lot of people are asymptomatic and they don't know that they have COVID. And also may have the sniffles or have a cough, but think, "Oh, maybe it's allergies. I have to go to work and take the train." And now they've exposed everybody on that train potentially to COVID.

(00:45:52):

So there's a lot of faults in how that processing and thinking and argument function. And without getting too into the weeds of the politic and all that stuff, it's pretty clear how that has been laid out. So these things are continuing to develop, and unfortunately the people that are going to be the most impacted are the people like myself that are immunocompromised. Before I even had long COVID, but have further become at risk to worsening my long COVID symptoms and getting COVID again for people who have been really vigilant about not getting COVID to begin with and have since not had COVID these four years because they've isolated the past four, almost five years that we've had COVID.

(00:46:41):

Right? It's going to impact those folks most who may only leave their house staying at groceries or may only have to go to the doctors and they wear their mask or have to go on the public transport because they don't have a car and they need to get somewhere and they wear a mask to protect themselves, or a loved one they have at home who has cancer, is getting chemotherapy. There's a whole host of people, not just people that are just

wearing a mask for broad community care or just for whatever reason. There's so many people, even before COVID, that wore masks to keep people safe.

Keith Casebonne (00:47:19):

I was making the same point. This is not new.

Maddie Crowley (00:47:21):

Exactly. What's so infuriating is that this politicization of mask happens here. It doesn't always happen elsewhere. So I had the wonderful opportunity to travel to Japan a year ago, and it was a trip of a lifetime, whatever. Everybody on public transport, or 90% of people, again, still during the pandemic as it's still ongoing, yes, but they all wore masks because they have the sniffles. They don't want to get their friends sick. It's very basic.

Keith Casebonne (00:47:52):

Wow, how refreshing.

Maddie Crowley (00:47:56):

[inaudible 00:47:53] It's just, "Ooh, I don't want to get someone else sick."

Keith Casebonne (00:47:59):

Caring about other people.

Maddie Crowley (00:48:01):

Why would you want to get someone else sick? You don't know what that person has going on in their life. You don't know what type of family member or loved one or friend or whoever they might be caring for. If they're a doctor, then you might get them sick and they might take it into a medical facility where those people who go and patients are already at higher risk because of their conditions. All of these different things. So like we're saying, the argument for mask bans devolves very quickly, and the movement against masks devolve very quickly, and it becomes a very politicized argument more than anything.

(00:48:37):

So we just wanted to talk about that because unfortunately, it's going to hurt disabled folks, folks with multiple marginalized identities, folks who are low income, houseless folks, people living in congregate settings, people living in nursing homes, all of the most vulnerable folks are still the folks that are the most at risk. So all of that to be said, there's a

lot of ongoing frustrating things for especially someone like me who has long COVID that is trying my best to keep myself safe, keep my community safe, and other people that I care about who have chronic conditions, even without COVID involved.

(00:49:23):

Just basic community care, that now it's being harder and harder to keep us safe, which is ultimately just... It's unfair and it didn't have to be like this. That's at the end of the day how I feel about it. I am a young person. I'm in my mid-twenties. I think I have a lot of potential in the work that I do and the things that I care about and my talents, but these things that are being introduced are really hard because they could really change what my life course could be like just because I am more at risk to get COVID again.

Keith Casebonne (00:49:57):

And those individuals who maybe have not had COVID but still have a preexisting condition or a disability or something, any other reason why they should have the ability to just choose to wear a mask so they can continue to keep themselves healthy and safe, and to have a law that prevents them from doing that is... It's gross, honestly. And it's-

Maddie Crowley (00:50:24):

It's not just COVID. There's tons of other things in the world. If I don't have to catch the flu, why would I want... If I can avoid getting water droplets on my fingertips or droplets with a virus or flu or common cold or whatever, and I touch my face, if I'm wearing a mask and I can protect myself from getting something that's just going to make me sick for a week or something, why would anybody want to get sick at the end of the day? At a bare minimum, take everything else out of it. Why would you want to get sick or help other people or make other people sick?

Keith Casebonne (00:51:01):

I could go on and on about the aspect of crime related to this which I think is just absurd because crime is down at a rate that is the sharpest decline in a long time. And yes, when we were under the pandemic, crime rose. It has gone down a lot. And so people who still had the freedom to wear masks at that time. So there's no logic in this, I'm sorry. There's no logic in saying that this is something to make it harder to commit crimes. People have been wearing masks, again, like you said, long before COVID. Just because someone maybe has cancer or they have a family member with cancer or whatever the reason is, and they're protecting themselves or their loved ones.

(00:51:45):

To me, that's for appearance. To me, that's putting resources to supposedly fight crime, it's resources put in the wrong direction just to make certain people feel like they're safer, when really it's doing nothing except hurting other people. Anyway. This is not an episode about crime so I won't-

Maddie Crowley (00:52:04):

That's a good way to say that.

Keith Casebonne (00:52:09):

Well, it's ridiculous, but on a much more refreshing, happy note, and this is a loaded question if I've ever asked one. So when you are dealing with these flareups and you're hungry and you got to eat.

Maddie Crowley (00:52:23):

Really loaded question.

Keith Casebonne (00:52:24):

I'm forcing this aren't I?

Maddie Crowley (00:52:28):

How much do we load? What kind of cheeses do we put on that? What are you putting on it? Let talk about mac and cheese. A grilled cheese. Have you ever had that?

Keith Casebonne (00:52:39):

No, but it's almost lunch and I'm thinking it's interesting.

Maddie Crowley (00:52:45):

It's good I've had it before. No, but in a much more serious conversation. Right.

Keith Casebonne (00:52:52):

Right.

Maddie Crowley (00:52:55):

And like you mentioned, these folks who do Pod Access, which is a great newsletter for deaf and disabled podcasters doing this grilled cheese challenge, how can you bring grilled cheese into the conversation? In the email, they mentioned how this person talked about their mom, a family member who would make grilled cheese for them, and almost paying homage to the story of their life of how grilled cheese played this relationship with their family and stuff. And it was actually really beautiful. It was interesting.

(00:53:33):

But as we were talking about this podcast and chatting a bit about long COVID and somehow tying together grilled cheese, it became very evident to me that for folks with disabilities, or you just had a really long day, there's a couple go-to meals out there for people. For me, I love a good cheese and crackers. I don't know why I love cheese and crackers, which is essentially a grilled cheese deconstructed, right?

Keith Casebonne (00:54:03):

Deconstructed un-grilled.

Maddie Crowley (00:54:05):

Exactly. So as we were talking about it, and as I was going through my long COVID flareup, I was thinking grilled cheese is actually... Grilled cheese and soup is one of those, if you were sick growing up and your family or loved one or a friend helped make you feel better, you might eat a bowl of soup with a little grilled cheese or a sandwich or something. And that actually has become such a big, long COVID flareup sick meal, disabled meal in my household because it's so easy to make. It's so yummy.

(00:54:39):

It's filling, it's nurturing, it's literally lunchtime, and I'm actually going to make one after this because I started to make myself hungry. I'm going to be so honest. I love eating it with-

Keith Casebonne (00:54:50):

This is the problem of working in the office, is that I don't have the flexibility to go make myself a grilled cheese right now for dinner.

Maddie Crowley (00:54:54):

Perks of working from home.

Keith Casebonne (00:54:54):

That's right. That's right.

Maddie Crowley (00:55:00):

Controversial, I grew up dipping my grilled cheese in ketchup.

Keith Casebonne (00:55:06):

Now that is a controversial hot take right there.

Maddie Crowley (00:55:09):

If you think about it's just cold tomato soup.

Keith Casebonne (00:55:12):

Cold tomato soup.

Maddie Crowley (00:55:14):

Let's normalize it. It's like that hot sandwich with a cold dip. I'm just saying don't knock until you try it.

Keith Casebonne (00:55:22):

All right. No, I think that's... The comparison of the soup, that's reasonable. That's reasonable. I can see it.

Maddie Crowley (00:55:29):

Thank you.

Keith Casebonne (00:55:29):

[inaudible 00:55:30] try that.

Maddie Crowley (00:55:29):

Thank you.

Keith Casebonne (00:55:30):

Yes, I can see it.

Maddie Crowley (00:55:31):

I've gotten a lot of resistance to my ketchup.

Keith Casebonne (00:55:36):

Some people have said that a grilled cheese is better instead of buttering the bread, you put mayonnaise on it. Have you ever... I've heard that.

Maddie Crowley (00:55:43):

No.

Keith Casebonne (00:55:44):

I tried it, and personally I didn't think it was... I went right back to using butter because for me, it wasn't the same. I just didn't know if you'd heard of that or tried it.

Maddie Crowley (00:55:53):

That's fair. I haven't. I think there's a certain sector of our population that loves mayonnaise, and I'll say, I like mayonnaise on a sandwich or a turkey sandwich, but people who put mayonnaise on everything, I personally don't get the appeal, but I guess I get it. It is maybe a more flavorful kind of butter adjacent thing. I've heard that if you butter both sides of the bread, not only the outside bread, but also the inside bread that touches the cheese, that makes a difference.

Keith Casebonne (00:56:33):

No, that's interesting. I've never tried that actually. I've always only done the outside. Now, let me tell you something, that I had the best grilled cheese in my life about a week ago. Seriously. My younger daughter made it for me, and she put shredded cheese pressed into the buttered side of the bread. And so when she grilled the grilled cheese, it had cheese, not like a slice of cheese. It's a sprinkling of it, but it has a little bit of cheese on the outside and it gives it a crust almost of cheese. And it was really good. Not good for you, but really good.

Maddie Crowley (00:57:11):

That sounds so good.

Keith Casebonne (00:57:13):

So that's another...

Maddie Crowley (00:57:13):

Wow. No. So I hinted at the macaroni and cheese grilled cheese.

Keith Casebonne (00:57:20):

Yes, you did.

Maddie Crowley (00:57:21):

I had this in, was it Tampa? I can't remember. I'll have to find it. And if I can link to the restaurant, perhaps folks in that area can go try it, but oh my word was it phenomenal. It was just like your classic bread on the outside and they used a nice thick brioche type bread and then they had mac and cheese, but it was a white cheddar. Oh my god. So delicious. Now I'm like, I think I have mac and cheese in my pantry. I think I might make a whole... I have to do a nice taste test. I might get into it tonight for dinner.

Keith Casebonne (00:58:08):

It's interesting. All right.

Maddie Crowley (00:58:11):

I think I'm going to have to. I'll keep you posted.

Keith Casebonne (00:58:11):

All right. That sounds good. No, definitely. It sounds amazing. And that sounds like something I'm definitely going to have to try at some point. That sounds really good. And talk about the combination of comfort foods. That's just comfort on comfort. That is wonderful.

Maddie Crowley (00:58:28):

So not just grilled cheese, mac and cheese, I'm very particular and my roommate and I call it the magic mac and cheese. So I don't know if you've had... I don't know if we can say, we're not really getting paid.

Keith Casebonne (00:58:43):

We're not sponsoring yet.

Maddie Crowley (00:58:43):

We can say brands on here.

Keith Casebonne (00:58:45):

Why not?

Maddie Crowley (00:58:46):

Annie's White Cheddar Shells boxed Mac and Cheese. Hear me out. After you've cooked the mac and cheese, you dump it out in the pan, you put a tablespoon of butter and just a splash of milk, and then mix the cheese packet into it. So primarily majority butter. Wow. And it has to be high quality butter too. It helps with the richness and the yumminess of it.

Keith Casebonne (00:59:23):

Oh my God, I can imagine.

Maddie Crowley (00:59:25):

I'm so hungry.

Keith Casebonne (00:59:25):

That sounds really good. I know, I know. Well, that sounds amazing. And I do love... I've had Annie's White Cheddar Shells and it is really good. I've always preferred-

Maddie Crowley (00:59:36):

I can't go back to Kraft.

Keith Casebonne (00:59:37):

The white cheddar version.

Maddie Crowley (00:59:38):

I can't do it.

Keith Casebonne (00:59:39):

Kraft does have a white cheddar version and it's good. It is good. But I could go interchangeable, honestly, between Kraft and Annie's. But I do prefer the white cheddar for sure. And that's interesting. I'm going to give to-

Maddie Crowley (00:59:51):

Once you go white cheddar, you can't go back.

Keith Casebonne (00:59:53):

You can't go back. And then you put that on some bread and grill it up. You've had an amazing... Oh, goodness. All right.

Maddie Crowley (01:00:00):

You've got a great sandwich.

Keith Casebonne (01:00:02):

I think we need to wrap this because we're going to start... I'll start eating my fist in a minute here.

Maddie Crowley (01:00:05):

I know. My stomach's growling.

Keith Casebonne (01:00:10):

I know, right? So there we go. We have managed to talk about long COVID and grilled cheese, and I think we did so in a very smart, respectable way.

Maddie Crowley (01:00:21):

I think it was very eloquent.

Keith Casebonne (01:00:21):

I think it was... Absolutely. And it is a comfort food, it's the kind of thing that when you're not feeling good and you have low energy and fatigue, you can actually whip up and make it. It's a relatively easy thing to make. So I think we get extra bonus points for that.

Maddie Crowley (01:00:34):

Bonus points.

Keith Casebonne (01:00:35):

That's right.

Maddie Crowley (01:00:36):

Exactly. Well, thank you for bearing with us and hopefully sticking with us to the mac and cheese grilled cheese conversation at the end here. We had fun brainstorming what this could look like. As you all know, if you listen to this podcast, we typically bring really... We try to do really well researched, really intentional episodes. And not that this wasn't well researched or intentional, but it was a bit more fun and allowed us to freeform, free talk this whole segment and gave us the flexibility and gave me the flexibility to recuperate. And as Keith and I do these podcasts, I do more of the planning and reaching out to guests and creating of the questions and things.

(01:01:21):

And Keith does, obviously, we share, co-host, and Keith does a lot of the more meticulous technology things, editing and all of that stuff. So we have a really good structure to how we do this podcast. But like I said, as I do that side of things, this really allowed me to have the flexibility to not stress too much and still get an episode out that we hope was informative but also a little funny and enjoyable too. And just try something different. So I hope you all enjoyed it, and if you did, please leave a rating, share it with your friends. Keep talking about long COVID. It's really important as these mask bans or other things especially begin to develop.

(01:02:07):

Unfortunately, people are going to continue to get sick and people are going to continue to get long COVID. And we want to make sure that people have the information they need to make decisions about their health and they're keeping their community and themselves safe. So yep, if you could share it. Also, we're on all of the podcast platforms, so if your friends or a loved one don't have the episode where you're listening right now, you can share that we're on other podcast platforms. And we also have the recording and transcript on our website so you can access it there along with all of our other podcasts that we've done in the past.

Keith Casebonne (01:02:46):

That's right. You can find that at disabilityrightsflorida.org/podcast. And again, we'll have show notes, links to as many of these things as we can. Even if we can find a good grilled cheese recipe or a link to a restaurant like we mentioned, we'll throw that in as well. So thanks for listening and please email any feedback, questions, or ideas about the show to podcast@disabilityrightsflorida.org.

Announcer (01:03:12):

The You First podcast is produced by Disability Rights Florida, a not-for-Profit corporation working to protect and advance the rights of Floridians with disabilities through advocacy and education. If you or a family member has a disability and feel that your rights have been violated in any way, please contact Disability Rights Florida. You can learn more about the services we provide, explore a vast array of resources on a variety of disability related topics, and complete an online intake on our website at disabilityrightsflorida.org.

(01:03:47):

You can also call us at 1-800-342-0823. Thank you for listening to You First: the Disability Rights Florida Podcast.