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Proem 00:52

During the hot and sweaty summer of 1972, I worked as a nurse's aide at the Detroit Psychiatric Institute. The veteran staff shunned and isolated this young, ignorant, white boy from the burbs purposefully leaving me vulnerable as I walked in the hallways in fear among young inner-city Institute residents. They expressed their psychosis with violence at the staff and each other. No air conditioning, old brick building, hot, hot, hot. Suddenly the Animals singing, *We Gotta Get Out of This Place (if it's the last thing we ever do)* piped in from the radio speakers into the unit. Everybody cracked up. The spell broke. I was safe for a few hours. Barry Man and Cynthia Weil wrote this tune in 1965. Initially, the song played at proms – getting out of high school. Soon military forces in Vietnam adopted it as an anthem, aching to go home from war. At 16, I started working as a draft counselor at a downtown church, learning the regs to help young men avoid the draft and soldiers to figure out how to get out of the army. I figured if I could learn draft counseling, perhaps I could avoid going to Vietnam. That experience with returning soldiers was my first with PTSD – Post-Traumatic Stress Disorder. Really, my second, as my parents were holocaust survivors. But I didn't understand they had PTSD at that time. But that's another story. Now, when I think of PTSD, I hear the Animals. Side note, the nurses at the Detroit Psychiatric Institute introduced me to the idea of becoming a nurse. I went.

I'm an upstream and downstream kind of guy. What led to this? What comes next? For Covid19, next is a tidal wave of PTSD from life disruption; hopes dashed; painful, unwanted intimacies; near-death experiences; fear and loneliness. A miasma formed by disaster. How can we, our families, communities, and healthcare systems prepare for this tidal wave? I fear it's too late to prepare. It's upon us now. However, we can begin to recognize it around us. I reached out to Nancy Michaels, my guest in August 2019 with Illness-Induced PTSD, my most listened to and read episode.

COVID-induced PTSD 05:12

Health Hats: Nancy Michaels. So lovely to be in this virtual space together.

Nancy Michaels: It's the new norm.

Health Hats: The episode that we did a year ago is one of the most searched for episodes that I ever did. Perhaps because it's got medical PTSD in the title or that together we're so glamorous.

Nancy Michaels: Let's not mess with perfection.

Health Hats: I wanted to touch base with you again. In this Covid world, there's a lot of attention paid to survival. I can't help but think, 'okay, we've survived. Great, now what?' Some people had a lifethreatening experience like yours on ventilators, dialysis, and more and then survived. Then life goes on. How do you deal with that? For some people, Covid has severely impacted their physical or mental health, and then they have to keep living. Then there's all their family and friends. You don't just go home, and it's over. I wanted to pick your brain about those different groups of people and what you've learned and your insights.

Nancy Michaels: I wrote an article on LinkedIn, my advice to medical professionals spending time with people in isolation in ICUs. It's horrific for those people that they had no family members with them during this time even though they may be semi-conscious or unconscious There is a knowing for anybody who's been on a ventilator that you do feel like you're going to die of suffocation. I can't imagine dying under those circumstances or living under them with no one speaking to them. Family members who lost people are going to have PTSD because of the way that this has been handled. I think it's changed since the beginning where people are now allowed to go in and speak to their family members, but that's very recent. That was not the norm going into this. Having that ability to do that for family members is incredibly important. I can't imagine being a patient knowing how ill you are, not knowing if you're going to come out of it, and then ultimately dying with no one around you who cares about you other than medical professionals. They're doing their job, and it's commendable. I can't say enough about what we're putting these healthcare people through, too. They're going to have PTSD as well.

Health Hats: Yes, that's a whole other piece.

Nancy Michaels: Our country is not prepared for this. Our mental health system is lacking. I know firsthand because I have a son who's on the autism spectrum who I believe is having more difficulties than that and needs another diagnosis. Just in terms of finding him the help he needs right now is almost impossible. I'm grateful that I have the wherewithal, the time, and resources to pursue the best line of treatment. I don't know that there is even that for most people. I had an advantage more than most. We haven't even talked about what you initially brought up with the people who were surviving and those family members. My heart goes out to the people who are dying with no family contact. Those family members never got to tell them how much they cared about them. It's my experience that medical professionals do a great job. Still, they are not necessarily doing a great job communicating with patients, especially ones that they view as unconscious or semi-conscious.

Health Hats: Say more about that. You spent more than a month on a ventilator.

Nancy Michaels: I was in a coma for two months. I was in ICU for three, but I probably was ventilated two and a half months. It took a month when I was awake to get off the ventilator - the most frightening month in my entire life.

The continuum of unconsciousness 10:28

Health Hats: Whenever I hear anything as dramatic as unconscious, I can't help thinking there must be a continuum from totally out of it, experiencing no sensation whatsoever, to living under the surface. Am I crazy?

Nancy Michaels: I have vague memories of certain people being there and knowing that they were there, but not being able to communicate. My mother said that when she came into the room, my heart rate would increase. She was nervous and went out and asked the nurse, 'should I keep coming or not? Is this upsetting her to know that I am here?' They said, 'no, you should keep coming. You should let her know that you're there. You should talk to her.' I do believe there is a level of consciousness, even as you are deemed unconscious. You can still sense somebody's presence. I do think that's true. There's data that shows it. The medical world wants data. My heart rate was going up even though I wasn't able to say anything. Some indications made it obvious.

Suffocating while coming off the ventilator 12:04

Health Hats: Say more about that period when you were coming off the ventilator.

Nancy Michaels: It was awful. I do remember that I would be the calmest when people were in the room with me, family members, and friends. As the day went on and they left, my anxiety level would increase. I had a lot of time to think. I knew what was happening, but I couldn't speak. I couldn't even ask a question about it. I was convinced that the ventilator machine was not working correctly. Something was wrong. I wasn't getting enough air. I kept thinking, 'After all of this, I am going to die of suffocation." That just frightened me, too. I wished that it had happened then, so I wouldn't have to go through this. Not one person, despite the exceptional health care that I received, lifesaving health care, not one person explained to me that my lungs had atrophied just like the rest of my body. To make them stronger, they had to watch closely and dial the machine down so my lungs would work harder to be able to breathe on my own without that support. Now, would I have believed that the first time they said it? Probably not. If every person who came into that room said that to me again, I think it would have sunk in. They can't all be wrong. People were trying to kill me — it's psychotic. I was on all kinds of medication. I didn't think that of everyone. There were a couple of people - I know their faces to this day, who were innocent bystanders to this whole thing because they weren't trying to kill me, but I was convinced. So, repetition helps.

Getting to home 14:11

Health Hats: You came out of it, and you went into Rehab right after your acute experience?

Nancy Michaels: Yeah, Rehab sucks for anybody who is wondering. It was awful. I was there for six weeks, and it was terrible simply because I was medically compromised. I should never have gone to Rehab. I should have been getting Rehab at Beth Israel (BI) instead of being sent somewhere else. I can't tell you how many times I'd come back to BI for different tests, CT scans, and MRIs. In the end, I was readmitted. I did six weeks in Rehab, but then I was readmitted back to Beth Israel, finally, on the transplant unit where I had never been before although I had had a liver transplant.

Health Hats: Now, many people have been in the ICU on ventilators with Covid. It seems like the tsunami of people is beyond the system's capability to manage. Now that gets pushed farther down the

line, along the continuum. There are all these people going to Rehab. There's probably a bottleneck. Oh, my goodness. I'm overwhelmed. My brain hurts. I'm overwhelmed with the downstream impact. Congratulations, you survived. I have a friend in Detroit who is a primary care physician who got Covid. He's coming out of 40 ventilator days, and I think, 'Okay, now what is he going to do? He lives alone. He's going to need Rehab, and then he's going home. It's not like you just go back and all of a sudden, you can cook and clean and check your email.

Micro-gratitude 16:42

Nancy Michaels: I am so grateful that at the time of my personal tsunami. I describe it that way because I was just divorced; my kids were six, seven, and nine at the time. But I was fortunate that my family was there for me. I ended up living with my parents, living with my brother and sister-in-law. She is a nurse. I remember thinking I've got to start feeling grateful for something. It was baby steps. I'm glad I can sit on this couch, and no one needs anything from me because I'm not able to do it. At least I can lay here, and I don't have to make myself somebody I'm not.

Health Hats: Micro-gratitude.

Nancy Michaels: Eventually, it gets bigger and better as time goes on. But I think for me it was a survival thing. I had to start doing that for me not to go down a very dark hole of being suicidal. I have such empathy for people who are alone in this. We started to talk before you started recording. Even if you're not sick and you're by yourself, it's difficult, let alone coming back from Covid. The world expects you to get over it. 'Thank God that's behind you. Let's not talk about that anymore that must be upsetting.' To this day, if I have any kind of procedure, I want Ativan the night before, I want it in the morning that I'm driving in, and I want to take it before that happens. I don't take Ativan any other time, but I start getting worked up at least a day beforehand. Now there is a better understanding among my medical team that there is an element of PTSD here. That's one way to deal with it. There are plenty of others like talk therapy and other things that I'm engaged in, but it's real. It is real.

Now a word about our sponsor, ABRIDGE.

Use Abridge to record your counseling visit. Push the big pink button and record the conversation. Read the transcript or listen to clips when you get home. Check out the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!

My family's PTSD 19:48

Health Hats: Let's talk about your kids and your parents. Start with your kids. Suddenly their life changed because you were gone and your family manages, they manage. How have you seen the impact on them?

Nancy Michaels: I still remember that time. I think my oldest two, especially, maybe not my youngest daughter, who's now 20 because this happened 15 years ago. She had turned six. This is so bizarre. I usually don't remember when I went in. At this point, I was probably in and out of consciousness or being put into a coma before the surgery because my surgery happened, I think, on the 21st. It had to

have had an enormous impact. When my oldest daughter, Ashley, was at Emerson College three or four years ago, she did a heartbreaking story. I think she was only nine at the time. She must have been incredibly scared to walk in and see her mother with half her head shaved. I had brain surgery while I was in a coma and hooked up to all of these continually beeping machines. She does specifically reference that. And she talks about the <u>Gordon and Betty Moore Foundation</u>, who invested millions in trying to make the ICU less frightening. I know that it had an impact on her. I feel grateful that when I was able to be with them, I stopped all work. There was no way that I could do anything at that point—for two years, getting up when they did, getting them on the bus, going back to bed. Getting up when they were coming home, doing homework, dinner, baths, laundry, and I did that for at least the first year. That was what my life consisted of, unless they were with their father, in which case I would stay in bed most of the time or catch up on laundry or try to. I couldn't go grocery shopping. I remember unless they were home so they could take in the bags. I was so physically weak. My son will say, 'we almost lost you.' He's very dramatic about it.

Health Hats: It's pretty dramatic stuff.

Nancy Michaels: I'm sure that it was terrifying. They were protected in many ways by my family. I had someone who had been a nanny to me, like their grandparents. They made it so that it wasn't this enormous transition for them.

Health Hats: You're talking about several years of acute post-experience. There are phases. You had whatever you went through medically, then you an acute cycle of Rehab. Then you came home with an acute phase of being home and trying to manage with your kids and just life. I'm just trying to get a sense of the arc of this.

Nancy Michaels: It varies for everybody depending on how severe or traumatic. For me, it was bizarre because I was so healthy until I wasn't, and then I was so unhealthy.

Health Hats: That's what people with Covid feel.

Nancy Michaels: Absolutely right. This can get you out of the blue, and then suddenly, your expectations of yourself change, too. I wanted to feel normal. I wanted to be doing normal things. I didn't want to feel so exhausted and depressed. No one wants to feel that way. I was grateful that I had my kids. I was grateful that I had to move out of our home. We sold our home. I had to buy another home in the same school district. I wish I hadn't felt the pressure. When you're ill, you make decisions that you're not thinking through all the scenarios. It was about a year of me being sick because I also was admitted 11 more times back to BI after I finally was discharged after six months and Rehab. I think that first year I just figured out how to get through the day. How do I take care of what I need with my kids and myself and get through the day?

A bit normal at Disney World 24:51

Going into the second year, I was feeling a little bit better. I decided to hire an au pair. I wrote a list of ten things that I wanted to accomplish, and I did every single one of them that year. The first thing was taking my kids to Disney World. They hadn't been, but I knew my me going there with the three of them was going to be impossible because of my son's challenges. For instance, we'd get to the front of the line, and he'd see a warning sign. And he'd be like, 'I'm not going on that ride.' I'd say, 'you don't have a

pacemaker, and you're not pregnant, so you can go on that ride.' But he saw the warning sign. I am not going on that ride. I spent 90% waiting with him for the girls to come out. But at that point, though, I did feel a little bit more myself. I had somebody who can run after someone if they take off, I can do more normal things. The help of somebody else being there gave me a lot of hope, and I was fortunate that I could do that. Because I was putting a lot of burden on my family, they were incredibly helpful. But that's a lot to ask of your parents in their late sixties.

Accepting help 26:40

Health Hats: This makes me think is that the kind of support that you got is going to be scarce for all these people who are dealing with post-Covid. What do you suggest for people to find the resources they need and then vetting them? Are these people charlatans, or does this information smell right? Then there's person-fit.

Nancy Michaels: One thing I would say, too, most of us have friends or someone you know, or a church group that we belong to, or some kind of community that we were involved in before becoming ill. It's easy for us to say, 'no, no, no that's okay. No, you don't have to drop dinner off. I appreciate it, but no, that's okay. Oh no, I don't want you to do laundry for me.' But now people have to start saying, 'yes, that would be so great.' It would make that person who was offering it feel great about doing it. There is no better thing than to help somebody out. They get a lot out of it. But I think we all have a tendency to say, 'no, that's okay, I can do it, or I'll figure it out. I'll Uber it to the doctor instead of going with someone.' Anybody who's listening to this podcast who can help somebody, they could step up and help, bring the dinner even if they don't want it. The worst thing that can happen is they'll get tossed maybe, but I'll bet you it won't. Or put a bag of groceries on somebody's door with the essentials. Would be appreciated by anybody,

Health Hats: It is amazing how what seems like small help feels enormous - just to know somebody cares.

Nancy Michaels: If you're on the receiving end, it is huge. I'm so glad I didn't have to run out for these eggs and bread and milk. I think we have to all start saying, 'yes, thank you. That would be great.' And if we're able to help someone, we should be doing that. My God, even if you don't know somebody who's ill, there are food banks that need your help. There are many places we can go. I would ask the medical staff what resources might be available. Call your insurance company or MassHealth or whatever your insurance plan might be. Explain the situation to them and resources that would be helpful, and how could you possibly access those? Chip away at that because you are going to end up very frustrated. I think if that's your mission to get something done in a day, it's not going to take a day to get done. Or if somebody else can make those calls on your behalf, let them do that.

Health Hats: Right, it's a whole different set of energy.

Nancy Michaels: Exactly. There's no playbook on that. There are many differentiating factors such as insurance plan that might be very different than mine, and what's included in that might be very different.

Health Hats: Right. And your community is different. It's overwhelming. Just thinking about it to me is overwhelming.

Nancy Michaels: It's overwhelming now because this has caused this ripple effect. It's not just the patient or the survivors of this illness. It is their family member members. It is the medical profession, too. My heart goes out to them. I think they had been buried now and in the beginning with fear about what was coming. Sometimes that's worse than just having to deal with it. The accommodations that they've had to make. Setting up tents outside and moving patients so that they have access to this entire floor that's going to be a Covid floor, and then going home and having to take everything off, get in the shower. It's wearing to see people dying around you every day is not an uplifting experience. My heart goes out to people in ICU having spent so much time there myself. It is a rare situation where somebody gets out of that alive. Most people are in ICU because they are critically ill, and the chances of their survival are not great. To do that day in and day out, even on a good day, in a regular, non-Covid or pandemic era is gotta be taxing and horrible in many ways. But to do it at this point where people are coming out of retirement to help, people are doing double shifts. They're taxed in ways that are unprecedented.

Health Hats: What should we be talking about that we're not?

Nancy Michaels: My article was about if people are ill and in ICU, if their families are not able to be there, I do hope that medical professionals during the time that they are in that room, will speak to those patients. And it's counter-intuitive, I think, to what they are taught to do, or practice regularly. But I think that because they're in isolation, those patients not knowing if anybody is on the other side of that. You're in the waiting area of that hospital or what? I can't imagine, I think I would be questioning my entire family, and if I had been alone and never saw him at that point, I doubt I could be wrong. I will. I believe that most people were never even probably told you're not going to be seeing your family members right now.

Health Hats: At first during Covid, when somebody delivered, there was nobody present. Then as time went by, they said, 'you can have one person attend the birth, partner or doula.' I wonder as we get more experienced with this, and we didn't have such a tsunami of people with Covid, not as worried about contagion and room for another person in crowded spaces where everybody gets a designated person, with a mini-training, and sufficient PPE.

Nancy Michaels: I think that this started initially because we didn't have the set up to allow people who were nonmedical into these rooms. So, instead of realizing now that we might, perhaps we should shift the status quo. I agree with you that it would be a valuable thing, not only for the family members to be present, even if only one person can do it.

Health Hats: Just to let everybody know, I saw mon, I saw dad, I saw sis.

Nancy Michaels: It's a lot of burdens to put on that one family member, but there are people, I'm sure who would want to do that. If one of my children had it, it would kill me not to be in there with them.

Health Hats: Oh, Nancy. These are really tough times.

Nancy Michaels: It is like nothing I've ever experienced in our lifetime.

Health Hats: Thanks for spending the time with me and with us, whoever's listening. I appreciate it. This is something that's tragic to have experience with.

Nancy Michaels: We have to do something about it or at least share what we do know, and maybe that will help. Thank you, Danny. It's so nice, just great, even though it's not face-to-face.

Health Hats: Well, someday. Someday soon. I hope.

Reflection 36:10

My mother, with PTSD from being in hiding during the Holocaust, only wanted one thing while she was dying: not to die alone. Aloneness craves connection. We can respond as communities and a nation and as individuals. However, seeking volunteers as New York did won't cut it. Thousands of counselors responded to Governor Cuomo's call. That was a band-aid or rope bridge across submerged ICUs and Emergency Departments, not a solution. I expect and fear that our mental health systems and governments, overwhelmed with the tsunami of PTSD, will not motivate the mental health-focused legislative disaster funding needed to support us, our families, and our neighbors. However, we can promote connection and inclusion. Basically: **Talk About It**. I recommend these resources. You can find links in the show notes: The Help Guide, frequently asked questions about helping someone with PTSD; In the Bubble with Andy Slavitt speaking with Jason Kander about his experience with PTSD; and Nancy's LinkedIn article. My advice is manage your own stress so you have room for being present; get help for the whole family if you can find it; exercise your patience and listening muscles; build small positive habits for both or all of you; and figure out triggers so you can plan management of those triggers with the person with PTSD. And bless you, you're in my hearts. This will touch all of us.