

*Contents*

Introducing Nancy Michaels 00:51 .....	1
Health is fragile 04:36 .....	2
Illness-induced PTSD 07:39 .....	3
Giving yourself the label of PTSD 13:57 .....	4
Seeking treatment for PTSD 19:35 .....	5
Can caregivers get PTSD? 27:12 .....	6
No harder job than ICU work 30:35 .....	7
Managing the stress you can 34:19 .....	8
Control when you're really sick 37:02 .....	8
Reflections 42:47 .....	10

*Introducing Nancy Michaels 00:51*

People who live with long term, complex chronic illness suffer from extreme stress and trauma together and alone. 'Live with' means 'they're my diagnoses, I'm the patient' or 'I'm caring for someone with those challenges.' 'Caring for someone' can be professionals or lay people, family and non-family, and sometimes community. The intensity of acute crises, rehabilitation, and maintenance (living life) all cause unforgettable and deep-rooted stress. Crazy-making stress. It's called Illness-induced Post Traumatic Stress Disorder (PTSD). I've heard that 12-25% of people who experience a life-threatening medical event suffer from PTSD. This doesn't include the caregivers or people who have complex illnesses that aren't classified as life-threatening. I'm sure it's a bigger deal. To explore PTSD, I asked Nancy Michaels to join us. She spent 6-months in the ICU, two-months in a coma, with a liver transplant and brain surgery to boot. She most remembers dignity and control or lack thereof. It affected more than her. Listen in.

Nancy is a successful business development consultant whose company produced web cafes, live events and customer loyalty programs for clients such as Office Depot, Staples, UPS, Constant Contact, and Xerox. Numerous media outlets such as Success Magazine, CNN, Fox, Inc.com, and The New York Post have featured Nancy. She was the first recipient of the Tom Peters "Wow Project Personified Award," a Fast Company cover story and received the Small Businesswoman of the Year Award by the Women's Business Enterprise National Council (WBENC). Nancy is an active participant on patient-related organizations including Beth Israel Deaconess Medical Center's ICU Patient and Family Advisory Council (PFAC), Massachusetts Health Quality Partners PFAC, and the American Institutes for Research (AIR) PFAC.

In this interview you will hear us talk about BI. That's Beth Israel Deaconess Medical Center in Boston. We'll talk about Nancy's trach. That's a tracheostomy, a tube put in the throat so that a breathing machine, ventilator can breathe for you.

**Health Hats:** Nancy Michaels. How are you?

**Nancy Michaels:** I am well

**Health Hats:** I think we met as part of Pat Mastors' Patient Voices then [Patient View Institute](#).

**Nancy Michaels:** Yes, we did.

**Health Hats:** I've been following you ever since, and I read your book, [Patient Speak, A Guide for Healthcare Providers](#), which I love. I can get so weary of health literacy talk without life literacy as a balance. The first is for patients. The second is for clinicians. And I felt like your book filled a gap. I've got it sitting right here, and I'll include a link to it on the show notes.

**Nancy Michaels:** Coming from you, I appreciate that Danny. I have been following you ever since meeting you as well.

Health is fragile 04:36

**Health Hats:** Thank you. Well, we have a Mutual Admiration Society, so that works. Where were you when you first realize that health was fragile?

**Nancy Michaels:** I was at a gym working out. I felt incredibly ill out of nowhere. I knew I was exercising more than I had been with a personal trainer at the time. I told her that I thought I was going to get sick. She said to lay down. She took my blood pressure about 15 minutes later. It was completely through the roof. I wish I had the exact numbers now, but they wouldn't even let me drive home. They were like you really have to call your primary care physician and get tested. So, I did and I went in for a stress test and they were like get off the machine very soon after I got on. So I went through a series of tests. I was in the local ER a few times in addition to seeing my PCP just knowing that something was really really wrong. Stupidly I got on an airplane to do a speaking engagement in Atlantic City. I was so sick. I could barely function. I got through it and got back to Boston, thank God. I really just wanted to get home. My friend picked me up at the airport. She took me right to my local ER where I had been seen three times over the past two weeks. I didn't want to go to all the way to Boston. It was a Saturday night. I thought it was going to be stuck in triage and I'd die. I wanted to be seen right away. The following morning, I was taken by ambulance at 5 a.m. to Beth Israel. I went right into the ICU. I knew it was serious. I had no idea it was as serious as it was, but I was extremely sick.

**Health Hats:** Did you have an experience early in life with health challenges in your family

**Nancy Michaels:** My dad was a type 1 diabetic. And diabetes is something that runs in my family, but other than seeing him have an occasional reaction and noticing a personality change, really not much. Honestly, I have lived a very healthy life up until then. Most of the people around me were very healthy. I think this is probably the worst thing that has happened to anybody in my family.

**Health Hats:** Let's get into that experience a little more. But first, now that you've been through all these experiences, what does healthy look like to you?

**Nancy Michaels:** Well, healthy looks like today. Thankfully I'm doing so much better. It's not taking your health for granted, which I think most of us do when we're healthy. Every day that I'm standing up and functioning is a good day for me. I take a lot of medication. My life has definitely been impacted, but it's better than the alternative.

## Illness-induced PTSD 07:39

**Health Hats:** That's from the liver transplant and all the sequelae of that episode you were describing? One of the things that that I see is that people at the center of care (when I say people at the center care, I mean patients, clinicians, and all the people that support them) they experience many terrifying health events. The medical term for having difficulty managing those terrifying events is post-traumatic stress disorder or PTSD. So you went through your well, maybe let's tell us a little bit more about your the. The journey you went through going into the ICU that you just described.

**Nancy Michaels:** I was there unconscious for less than a week before I was in a two-month coma.

**Health Hats:** A two-month coma?!

**Nancy Michaels:** Two months. I remember my doctor saying to me, "Nancy, you're in complete organ failure. We're working on this. We're going to take the best care we can of you. But, this is not good." Then I remember him coming back and saying, "okay your kidneys are functioning now, but you are going to need a liver transplant. And we need to find one for you." I was always an organ donor and happily so, but we never think we're going to be the recipient. Right. That was not ever anything I ever contemplated. The night before the surgery he almost elected not to do it because he thought I was too sick and I would die during the procedure. As you know in medicine, these organs are very, very precious and in-demand. Doctors have to be very careful about who they allow that gift to go to because there are so many people in need. I remember he told me or someone told me after the fact that he called my doctor who's now been with me for 14 years. He was about my age who had kids around my kids' ages. I was also going through a divorce, too, Danny. It was the ultimate tsunami. It was like everything that could have gone wrong was happening. He did say to my doctor, the surgeon, "I think we have to give it a shot. She's young. She's never been sick before. She's got three young kids. I think you have to try." Thank God he did. As it turned out, though, I did die twice during the surgery and the second time was longer than two minutes. They found a blood clot in the liver after they had already put it in. So, they had to take it out again and make sure there were no other blood clots and then put it back in. Clinically I had coded for more than 10 minutes. They were not sure what my cognitive abilities were going to be. They did tell my parents that. Then two weeks later I had brain surgery. Prior to the operation they had to drill a hole in my head to alleviate the pressure in my brain.

**Health Hats:** So how long were you in the hospital for with this?

**Nancy Michaels:** Altogether six months, but I was in ICU in a coma for two of those months. When I woke up I was trached (breathing tube), so I couldn't speak. That was the worst month of the whole process. I think that's really where my PTSD came from. It was the inability to speak and having ICU psychosis. That is a real thing. It's when you have delusional thoughts. I thought that people were trying to kill me. I thought that nurses were taking my medication. I was just in a complete state of angst, panic, and fear. It was especially bad as soon as my family left. Late afternoons, evenings., throughout the night until they got there was just the worst period of time. I have vivid memories of that still. I think part of it, too, is because I couldn't speak so I had nothing to do but think about all of these things. Without any ability to communicate them to anyone. I do think that people in the ICU are very special Medical Caretakers.

**Health Hats:** The people who work there?

**Nancy Michaels:** Yeah. They do know that people are not in their right mind given the drugs that they're on. It was a lot of inconsistencies to being in an ICU. At first when I first woke up, I was very frustrated that I kept falling back asleep. I kept telling my brother mouthing out to him that I was being overmedicated. I wanted to be taken off some of these drugs. Well as the drugs were being weaned off, Ativan, I was starting to have worse and worse panic attacks. So, I would want Ativan now. I know what it's doing for me. Give it to me. That was met inconsistently by people. Sometimes I would get it. Sometimes I wouldn't.

### Giving yourself the label of PTSD 13:57

**Health Hats:** So when did you give it the label PTSD? You're describing this many years later. When did it come into your consciousness that PTSD was something you were dealing with?

**Nancy Michaels:** Now I look back and think almost immediately. After I left ICU, I went to Spaulding Rehab and was there for six weeks. I couldn't even stand when I left BI (Beth Israel). Then I was readmitted back to Beth Israel with a failure to thrive diagnosis. I just was not getting better. I wasn't eating. I had an inner ear imbalance, causing me constant nausea. It was awful. I went back there for six more weeks before they discharged me. Then I move 55 miles away from my kids, with my parents in Central Mass. During that period over the next six months, I was readmitted 11 more times. Anywhere from two to eleven nights from for various complications. During that period I hoped I would wake up. I thought, "this is not happening to me." This is the most surreal thing I've ever experienced. This could not be happening. Any procedure I had during those six months when I was back and forth in the hospital was fraught with anxiety. I had PTSD then.

**Health Hats:** I'm hearing the evolution of having PTSD, but there's a moment that happens that you can step away in your mind for a moment and think. "this is so not right. There's a name to this." When you started being conscious that you yourself had PTSD. I got it. In real time.

**Nancy Michaels:** Like what was the example? I remember exactly. It was when I had to have a biopsy during one of my return hospital stays. I was insistent that my doctor do it. I did not want anyone else to do it. I know that I annoyed this intern. It's a teaching hospital, I get it. But to this day I will not let an intern touch me.

**Health Hats:** So, you were finding yourself feeling like this is really an outsized reaction?

**Nancy Michaels:** Listen I've been in here plenty of times. Plenty of people who are not the attending had treated me. I had a mistake happen with an arterial line infection that an intern and Resident were attempted to do and they didn't do it correctly. It still is an exaggerated fear of somebody not having a lot of experience. I remember this woman looking at me and asking me all of the questions that the nurses asked prior to it. I answered her and I said to her, "This isn't personal. But if you read my chart, you'll understand. I have PTSD.

**Health Hats:** So, that's the moment you remember putting a label on it.

**Nancy Michaels:** I first vocalized it then. God help you if my kids ever got sick because they would not want to be around me in that situation. I would be a very strong advocate for my children. Not that my parents weren't, but it's a different generation, too. There was nothing that they suggested that my parents questioned in any way.

And now a quick break to hear about our sponsor, Abridge. I see many clinicians on a regular basis, way too many. I'm appalled at how little I can remember when I get home. My wife asks, What did she say? What about this medication or that test? I'm happy to remember half of it. To help me remember everything, I downloaded a new smartphone app called Abridge.

Now, when I go to the doctor, I ask if it's okay to record our conversation. Nobody has said no yet. I push a big pink button to record, and after I'm done, the transcript from our audio appears -- not the whole thing that's too much, but sections around medical keywords like fatigue, pain, tests, exercise meds. Now when I'm done, I can share my visit with my wife, and she can listen to exactly what the doctor said. Abridge was created by patients doctors and caregivers. Check out the app at [abridge.com](http://abridge.com) -- a b r i d g e .com, or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!

### Seeking treatment for PTSD 19:35

**Health Hats:** So when did you seek treatment for PTSD, specifically, as opposed to organ issues?

**Nancy Michaels:** As soon as I was in a situation where I was discharged after the six months. It was incredibly frustrating. I remember in ICU, there was a doctor who would come in and because I think people knew that I literally was suicidal. I just didn't think I could do it. I thought I had this is just too hard. I don't think I can do this. She would come in and say, "are you feeling suicidal?" and I would nod my head. And she would stay with me and then she would get up and leave. Without saying, "Nancy, you have every right to feel that way right now. You have gone through a lot. Like this is way more than what most people have to go through with their life. And what we're going to do is give you some medication to make you less anxious and when this trach comes out and hopefully it will be soon. You'll be able to talk to someone because that's really important and I recognize that not feeling heard it incredibly frustrating and especially when you have no voice."

**Health Hats:** So it's literally and figuratively, right?

**Nancy Michaels:** I just think like why come in? It is to irritate me? Why are you coming in to ask me this and then you're walking away and doing and saying nothing about it.

**Health Hats:** When the trach was out you realized you have PTSD and needed help? How did you find somebody that was a good helper?

**Nancy Michaels:** Well, I had been seeing a therapist prior, so I just went right back to her.

**Health Hats:** So, you had experience with somebody. Was that person you had experience with helpful? What about what she did was helpful?

**Nancy Michaels:** I do think showing empathy is showing compassion, showing understanding. This was so frightening. She understood it or made me feel that this was not completely abnormal. She normalized it for me in a way it didn't even matter to me., Danny, honestly, I didn't care if it was normal or not. It's just the way I felt. Even to this day, I definitely recognize him and if I had any kind of procedure at all, I need an Ativan the night before. I need an Ativan on the way in. I need an Ativan when I'm two minutes away.

**Health Hats:** You figured out that - this is using the wrong word - this is sort of a steady state. Maybe you've had counseling, but counseling does not make it go away. Counseling maybe just normalizes a little bit. Then you know that something's going to happen to you with triggers. These help you. One of them is when you have a procedure - Ativan.

**Nancy Michaels:** That and having my doctor do it. I said to him, "if I if I have to have another biopsy you're going to do it, right? I'll wait for you to do it. I don't want any more trust with somebody else. I think that's a sign of PTSD - to not trust. Okay. It's not trusting more than it is trusting.

**Health Hats:** Now in your travels and the work that you do, how do you recognize that somebody has PTSD? When you're just living and have an interaction and you say, "oh my goodness I recognize that!"

**Nancy Michaels:** Well, it's an reaction to something often times. I have a friend who was in the military and I think that she's done and seen things that I can't even imagine in my lifetime. But then other instances in her life that are really like not a big deal, she completely has the most over-the-top reaction. I often say to her, "Elizabeth, I don't get this. I could never do have done what you did, but this is kind of like an everyday sort of getting through life situation that really trips you up." I think it's manifested for different people in different ways. But I think it's going to be an over reaction. Or a real fear. It's something that may or may not be completely legit, but in that person's mind it is right.

**Health Hats:** So from the outside, it looks like an outsized reaction. From the inside, it's a trigger? My mother was a Holocaust Survivor. She spent her teenage years in hiding in from the Nazis. She absolutely had PTSD and she had triggers. Growing up I had no idea, obviously. But once I became an adult, I could put that together.

Do you think that people can recognize PTSD in themselves?

**Nancy Michaels:** I can tell you I don't think my friend does at all. I don't think she makes any kind of association with that. I think for different people it's also different. I've always been interested in Psychology, too. I think that that's why I realized in that moment when I said, "this isn't personal. If you read my chart you would know that I have PTSD. That's why I'm taking such a hard stance on this." It depends. My mother in a lot of ways has PTSD. She had a brother who died when she was 20. He was 21. They were incredibly close. I think in a lot of ways, emotionally she doesn't go there when you would think it would be natural to have a reaction that would be emotional. I think for her it manifests itself in not reacting. Kind of not expressing emotions. I think differently. Which is why you don't really have a good medical team who could recognize that as well; it's not going to show up for everybody the same way.

[Can caregivers get PTSD? 27:12](#)

**Health Hats:** So one of the things that I see in my work is that I tend to gravitate to the vacuum. So when I say that, I mean I'll focus on the caregivers, when there's a patient who's really sick. I think about who's taking care of the caregiver? How are they being taken care of? So do you think that caregivers and families can have PTSD?

**Nancy Michaels:** Oh, absolutely. I think even even in the situation with my mother, too. She can't remember so much of what happened to me that I have vivid memories of. I'm like, "really, you can't remember?" I think she just has blocked a lot out. "No," she just said, "I'm so glad that I didn't know

what was going to happen to you because you're better off not knowing. If I had known this was going to happen and it would be that bad, I don't think I could have tolerated it.

**Health Hats:** Yeah, so what would you recommend in your work about how to approach either patients or their families or caregivers who you're seeing signs of PTSD? How do you relate to that? How do you interject yourself? How do you approach that when you see it?

**Nancy Michaels:** For instance, with my friend I have said, "I think you are experiencing some PTSD. I know it seems very unrelated to what you've been through because it's a completely different situation. But I do think that's part of it." I don't necessarily have a lot of experience, honestly, Danny with other patients or caregivers to call them out on it. Or say have you thought about this? But certainly with people in my own life, I feel like I've been able to say I think this is PTSD or some form of having traumatic experience for the worries. When you do say that to people you're close to like my mother is in denial. She is like, "no no, no, no. No, it was horrible what you went through. That was a terrible thing. It was an awful time, but I don't have that." I think Elizabeth, too. I think it because it's so disassociated with the things that she did in the military that were so incredible and incredibly difficult that she doesn't make that association. I really do. I think that it's just more intuitive for me. That they have a sense of that - whether or not they would agree with me - is something else. I think that it's really important for medical professionals to get this kind of ability to see and to understand.

**Health Hats:** To see it in patients or ability to see it in themselves?

[No harder job than ICU work 30:35](#)

**Nancy Michaels:** Both. Listen, there's no harder job in the world, as far as I'm concerned to be in the medical profession. It's incredibly stressful. It's got to be. I remember going back to the ICU and having people cry when they saw me. Many of them I didn't even recognize.

**Health Hats:** You went back to people who had taken care of you in the ICU?

**Nancy Michaels:** Yes. I mean people found out. My doctors found out. They were like, "that was so good of you to go. There are so few people who are as sick as you are who make it out. Let alone come back and see them. I don't do it often. They have a support group that meets at the transplant unit every Wednesday at noon. I've gone to a couple of meetings since this happened. I almost feel like I don't want to scare anybody else. My situation was so completely over-the-top, not normal. Most transplants do not go the way mine did. I don't want to scare people.

**Health Hats:** Scare people because there's different intensities of trauma and reactions to trauma and you feel like you're an outlier and sharing your experience will freak people out?

**Nancy Michaels:** Yeah, especially some of these people who are on the waitlist and final exam. They haven't even had the transplant. Others have just recently had it and they feel like shit quite frankly. Hearing that I was sick for as long as I was. I meet now with the social worker. She'll set it up: "you cannot believe what this woman went through and she's here and she's doing really well. So that's the good news. What happened to her, the chances of that happening to anybody else, are so unlikely." She sets me up. And I don't get into the detail that I did with you for that reason.



**Health Hats:** Let's say this friend of yours all of a sudden had a Eureka moment and goes, "man I have PTSD. I need some help." How would you advise her to go about getting that help.

**Nancy Michaels:** Well, I already have despite her denial of having PTSD. I've said, "I think it might be good for you to talk to somebody about some of these fears." Quite frankly, I haven't said this to her, but I think they're irrational fears. They don't make sense in the real world. You may be dealing with something else, behind this under this. It's better to at least have the ability to share that with someone so it can help you navigate.

See the show notes or my website [www.health-hats.com](http://www.health-hats.com) and click on blog/podcast for more information, to subscribe or contribute. If you like it, share it. Thanks.

#### Managing the stress you can 34:19

**Health Hats:** I have had no experience like yours, but I do know that when my son was dying I found a grief counselor. It took me a few tries to find the right person. When I went to the person who I ended up working with, one of the things that he said to me was, "there's stress you can manage and their stress you can't and grief is stress you can't manage. There it is. So our job first is to manage the stress that can be managed so that you have more space to deal with this stress that you can't." I don't know if I bonded with that because it works for me or whether that's a feature of good counseling for grief. It seems like PTSD is monster grief - grief for yourself.

**Nancy Michaels:** I don't feel like it's a day-to-day thing. For me it's very much connected to when I'm in the hospital for a procedure. I start freaking out and that's what it is for me. I don't feel like every day I'm hit with this. There are times when I think about it and I get depressed or down or think of, my God I don't even want to go there. What is the point in thinking about this? But it doesn't paralyze me, I think I make a lot of demands or requests and ways that I want things to go. I think that is because of what I've been through and I do think it's a form of PTSD. But I wouldn't say that I live with that every day of my life.

**Health Hats:** That's good.

**Nancy Michaels:** Grief is the most difficult emotion. I actually resonate with what you said that this person said to you. Because I think that there are some things that are just beyond your control. I think maybe that's why it's so frustrating when you're sick. None of that is in your control. There's nothing you can do about that. That's frustrating, too, because it's just you really.

#### Control when you're really sick 37:02

**Health Hats:** Here's a little bit of a reach. Tell me if you think it is. Having control over your life is really important when you're not feeling well. Because feeling well is the way to feel more control. But if you're in the ICU or you're in the ED or have some kind of trauma, the people that are helping you, meaning doctors and nurses and whoever, can figure out ways to maximize those moments of control. Even if your intubated, I wonder if you know a strategy is figuring out how to maximize that control?

**Nancy Michaels:** I can give you an example of one segment. Listen when I was sick and I was awake that last month where I couldn't speak. They took the rectal catheter out. Never told me they were doing



that. I was stripped of all dignity. It was making me crazy that there was a lack of communication. Nothing was done with ill intent, I get that. People do the job. They do it over and over and over again. I think often times they just forget that for us as patient, it's the first time we're having it, not the one thousandth. All of that is taken away from you. The one request that I kept making was wanting to go outside. It was August and I kept being told, "you're too immune suppressed. We can't take you out right now." Meanwhile, being outside would be way better than being in a hospital. It was my nurse Frank who came early one day for his shift to take me down for a CT scan. And after that he took me. I was rolling through an area at Beth Israel I didn't recognize. I knew the routine after a while, what hallway I'd go through. I did not recognize where I was. Then he opened up these two big black double doors, and rolled me out onto the loading dock into the Sun, took the blanket off my legs, and just stood there for 5 minutes with me.

**Health Hats:** What a gift

**Nancy Michaels:** And it is the thing that I continue to talk about. It cost nothing.

**Health Hats:** It just makes you want to cry. How nice.

**Nancy Michaels:** Every time I think about it and when I speak and I tell that story I usually do. It was the nicest thing - other than saving my life. It was the nicest thing that anyone did for me in the hospital. There are so many things that can be done that don't cost any more money that really show that I was being listened to. That's why he took me to the loading dock. He couldn't take me out in front. That wasn't allowed and he probably would have gotten reprimanded, But in the end, it is the thing I still talk about 14 years later.

**Health Hats:** Yeah dignity.

**Nancy Michaels:** If somebody wants something that's easily given, why not give it to them?

**Health Hats:** Nancy, what should I be asking you that I'm not?

**Nancy Michaels:** I don't know. You're great. This isn't your first rodeo?

**Health Hats:** No, this isn't. I'm really glad we're talking. I feel so much that people, the sequela of being ill for people who have a really severe acute thing going on, Even if it goes on for a couple years. There's so much trauma there and then people who are chronically ill and are living it with no apparent end in sight. I don't really care what we call it, but it's traumatic stress.

**Nancy Michaels:** It is. And it's something that you never forget. It's not like you can get over it.

**Health Hats:** There's not a cure.

**Nancy Michaels:** Not a cure for this.

**Health Hats:** I could see that with my mom. To the end, it was there.

**Nancy Michaels:** And how could it not be?

**Health Hats:** Right. Well, thanks Nancy. Thank you. I'm so glad we got to do this.

**Nancy Michaels:** Me too. Thank you very much. I'll be talking to you soon.

#### Reflections 42:47

I'm seeing four clinicians over these few weeks. I think, what a pain – having to spend this valuable time in life schlepping to and fro, waiting, explaining, listening, worrying. On the other hand, they're my team. They're good. I need 'em. Layer on PTSD, if you have it. There's no appointment to have PTSD. It's unexpected, cyclical, and draining. Nancy's experience tells a story of PTSD. Her's trigger by procedures. Others by war. What about caregivers? Our families and our doctors and nurses? Who's taking care of them? See the show notes for some resources. Please share this podcast with those in need. Nancy said a lot here. The one thing that keeps hitting me: a tiny bit of control (the sun on her legs) goes a long way. Could that be why her PTSD is limited to procedures? Later.