HEAR ME NOW Podcast - Ep. 069 - Clearing the fog

Seán Collins (00:03):

Earlier this month, the WHO marked a milestone

Tedros Adhanom Ghebreyesus (00:07):

With great hope, I declare COVID-19 over as a global health emergency.

Seán Collins (00:15):

But in making that announcement, Tedros Adhanom Ghebreyesus was quick to add that COVID-19 is far from over

Tedros Adhanom Ghebreyesus (00:24):

Thousands of people around the world are fighting for their lives in intensive care units and millions more continue to live with the debilitating effects of post COVID-19 condition.

Seán Collins (00:36):

On today's program, we focus on the post COVID-19 condition with a conversation with Dr. James Jackson, who's been working with long COVID survivors at Vanderbilt University, from surviving to thriving with long COVID and "Clearing the Fog" today on the Hear Me Now Podcast, I'm Sean Collins. So glad you're listening.

(01:09):

James Jackson is a psychologist and the assistant director of the ICU Recovery Center at Vanderbilt, an associate professor of medicine at the Vanderbilt University School of Medicine. Dr. Jackson is the director of long-term outcomes at the Critical Illness Brain Dysfunction and Survivorship Center at the Vanderbilt University Medical Center. His book, "Clearing the Fog", has just been published by Little Brown Spark and he joins us now from Nashville. Dr. Jackson, welcome back to the Hear Me Now podcast. It's great to have you here.

James Jackson Psy.D. (01:44):

It's great to be with you, Sean. Thank you.

Seán Collins (01:47):

Let's start with a working definition. When you talk about long haul COVID or long COVID, what do you mean?

James Jackson Psy.D. (01:56):

It's a really interesting term, long COVID. It was coined as you know, initially by patients, and then it caught on, it caught on like wildfire the term. And there's a lot to like about it, but it's quite imprecise. People are not exactly sure what it means. For me, it generally means that you have persistent problems of a sort that you didn't have before, and those problems are due to the effects of having COVID. Now, it gets a little bit complicated. For example, there are people who have depression due, I think, to COVID, but they had depression before. Is that long COVID? There are people who have cognitive problems now. They might have had them before. Is that long? COVID? We can debate around the edges, I think. But in general, the definition is a situation where you have new health related challenges, often in the realm of fatigue, often in the realm of cognition, often in the realm of mental health that you didn't have before, having COVID that are due in large parts to COVID or to the effects of COVID, that, in effect is long COVID.

## Seán Collins (03:16):

As a journalist, I've been acutely aware with this pandemic that for the past three plus years of watching a social and medical crisis reveal itself in real time. That much of what we know now was unknown to us 24 months ago, or 30 months ago, or 36 months ago. And I think most of us understand that we've been learning about this virus and the illness that it causes as the world moved through the pandemic. We've, we've learned by going through it. And yet there's stigma attached to the kind of amorphous parts of this illness, and especially the long COVID, the sort of sequelae of the initial infection. There's stigma attached to it, and that surprises me a little bit because the whole history of the disease has been one of un unfolding new revelation.

# James Jackson Psy.D. (04:26):

I agree you would hope that we would be beyond that, that we would be beyond this place of stigma as a society. But I think COVID has revealed that we're not, it's revealed some unflattering things about us, I think as a society, and we interact with patients regularly who say that the feedback they get from family members, sometimes from friends is try a little harder, you know, buck up, lean into it, toughen up those sorts of themes with the implication being that your long COVID, these amorphous symptoms that you mentioned that are hard to quantify, that those are reflective of a character problem, that those are reflective of an unwillingness to work hard, an unwillingness to get out of bed, whatever the case might be, that hard work is the solution. And it's really a problem that so many patients are shamed in that way.

## (05:23):

For a variety of reasons. It's a problem, but partly because that shame leads to more depression, it leads to more P T S D, it leads to more stress, which in turn exacerbates these amorphous physical symptoms. It's really a vicious cycle, this cycle of shame. I think the other thing that I've noted related to stigma pertains to the mental health space, and that is that a lot of our patients, they are depressed, they are anxious, but they're really reluctant to give voice to that, even though clinically it's really important, they're reluctant to give voice to it because they're afraid that if they do, their healthcare provider, someone in the family is gonna say, aha, I knew it all the time. This is just anxiety. This is just depression. So, because they don't want that to happen, they hold onto this, they don't share it. And it's really sad because there's freedom in being vulnerable about your struggles. There's help available, but because that is often the gateway to being shamed, the gateway to gaslighting, they keep those struggles inside and it hurts them in the process.

### Seán Collins (06:35):

That understanding that you have reluctance really does speak to a broader stigma that attaches to behavioral health in general.

### James Jackson Psy.D. (06:47):

It's a tremendous problem. I think if there's a silver lining feels strange to use that word, and that might not be the right term here, but if there's a silver lining related to the pandemic, it may be that we're having conversations about mental health a little bit more often. I think we're talking about it more freely. But sadly, that stigma, which existed in spades before, it's, it's dying a, a, a hard death. We're not really making as much progress as we would like in reducing stigma. I certainly have found that myself. I, I've, I've talked openly over the last couple of years about my own battle with mental health. I have obsessive compulsive disorder, and it took a long time, a very long time for me as a thoughtful mental health professional who should have a different view. It took a long time for me to be willing to take the mask off and share openly about my own mental health struggles. So I think if it's a challenge for a psychologist to do that who should know better, it's a huge challenge for John and Jane Doe. And for your typical COVID patient we encourage it. We invite it. I try hard to model it, but it's still a difficult hill to climb for them.

#### Seán Collins (08:06):

A lot of your learning about long COVID has come from group sessions that you've hosted at Vanderbilt for people who who have had COVID. Tell me about that process of gathering those

folks. And I think in the beginning it was done almost entirely virtually, and I don't know whether you've, you've ever migrated towards in-person meetings for those groups, but tell me about that process.

## James Jackson Psy.D. (08:36):

It's really been an interesting process, these support groups and of the things that I've been fortunate to do at Vanderbilt in the last 22 years or so, I think the support groups is probably the one that, that I'm the proudest of, probably the one that has been the most impactful, I think. And it started really, it started prior to COVID, probably six or eight years prior to COVID. We had decided that ICU survivors, again, long before COVID, that they needed a forum for support. And there really wasn't one. There were a few support group networks in the United Kingdom and in Europe, but none in the United States. So we started a support group. It met in a tiny little church. It met in person, and two or three people would come, and then four or five, it grew a bit. And by the time the pandemic emerged, we had been running this support group really effectively with 20 people or 25 every week.

# (09:32):

And so I had the sense I wasn't exactly sure, but I had the sense that the, the same dynamic that we saw in our ICU u survivors would probably play out in people after COVID. That they would equally need support and that a support group would equally be helpful. That's what I thought. And so it was a lot like the famous concept in the movie Field of Dreams. You know, if you build it, they will come. We, we decided we would start the support group. We decided we would start one, not hugely ambitious, we would start one. And word got out about it. Initially the plan was it was gonna be very didactic. We were gonna teach people cognitive rehab in a support group, and I think that's useful and, and important. And we started down that road with patients. And what we heard from them by week three or four was, you know, this is helpful, but what we really crave is just support.

# (10:28):

We just need support. People are not listening to us. We're feeling disenfranchised, we're lonely. We need support. So we really morphed it into a pure support group, a pure peer support group. And before long that support group had grown. It was 16 or 18, close to 20 people. We started another one. We started another one. Now we have one support group for ICU survivors, some of them people who had COVID in the ICU. And we have about four other support groups, one for family members of people with COVID, and then three for people with long COVID. So every week at Vanderbilt, it's all virtual. We have close to a hundred patients

from all over the United States, from Canada, from Wales, the United Kingdom, who come to these support groups. And I think they find a place to be cared for.

## (11:23):

I think they find a place to be nurtured. I think importantly, they find a way and a place to be challenged. It's, it's two things. It's for the support of patients, and it also is for their growth. You know, we offer a, a safe place for people to take their mask off, and we try to help people gain tools and techniques, ways of thinking about things that are gonna enhance their experience. And frequently the feedback we get, I mean, we're not, you know, we're working on improving these groups all the time, but the feedback we get is that these groups have been a virtual lifeline for people. That this has made a gigantic difference in the lives of people. And it's a model support groups that has worked as you know, in other medical populations. It's one that we are trying hard to replicate in long COVID.

## (12:14):

We have a waiting list of 45 people. We'll eventually call that list down. We'll eventually start another group. I I consistently want to add another and another, and my saner colleague say, you know, I think five is enough right now. And I'm careful to listen to them. But it's a model I think that improves the quality of life of people with long COVID. It helps them see that there is hope because they see pe people in the group who are improving. And that's one of the most important messages I think, that if you hang in there with this, if you persist in this, everything isn't gonna be perfect, but you're probably gonna get better. That's what they see in the group.

# Seán Collins (12:59):

I know that you work with full compliment of researchers, including data analysts. I'm, I'm curious if you all have tried to quantify the therapeutic benefit of the groups.

### James Jackson Psy.D. (13:12):

We're in the process of trying to do that even now, but we don't really have any results as such about the effectiveness of the group. At this point, it's really anecdotal. We very much would like to design some pre and post sorts of studies that tell us how much the group, the group has helped people. The reality is we're drinking out of a fire hose during this pandemic most every day, it seems. So the research we would like to fully integrate into the groups we haven't completed yet, but the, the anecdotes, at least that we hear are that these groups change the game for people, for many people. And I think that's because as you're aware, as other people

have highlighted, there's an incredible dynamic of loneliness and isolation that occurs in the context of long COVID. And, and that could be for very literal sort of physical reasons.

(14:09):

That is, you're not working, you live in rural Tennessee, and you literally are isolated. Or it could be a little bit more abstract. That is, no matter where you are, you're feeling very much like you're not a part of things because you're the only one in your household that has long COVID. You're the only one, you know, perhaps other than peop the people in the group that have long COVID. So the isolation is a problem. It breeds physical problems. It breeds mental health problems. It breeds cognitive problems. And the group, I think, is helping change the game with regard to that isolation. And we often point out, you know, the isolation is not your friend. There are introverts, there are extroverts, and we're not trying to change people from one to the other, but we are trying to remind people of the value of social support. You know, there's a vast medical literature, there's a vast literature that looks at studies done with animals, for instance, whether it's animals or humans, more social support is better, less social support is worse. So that simple equation is the equation we see unfold all the time. We see beautiful friendships unfold in the context of this group and their friendships that have teeth. I mean, this is commitment that has teeth. It's profound and it's deep, and it's lovely to watch.

Seán Collins (15:36):

Wow. And, and as you said, it crosses borders of all sorts.

James Jackson Psy.D. (15:40):

Absolutely. it's it's lovely to see people from diverse backgrounds and communities whether it is ethnic or racial, economic, geographic, whatever reaching across those lines to really care for and support each other. It's really been beautiful.

Seán Collins (15:59):

I'm talking with Dr. Jim Jackson today. His book, "Clearing the Fog; from Surviving to Thriving with Long COVID' has just been published by Little Brown Spark. At one stage in the book, you make a point when discussing a patient named Charlie in his recovery. You write, "his life is no picnic, but he'll be the first to say that he's thriving, not merely surviving." What's the difference?

James Jackson Psy.D. (16:28):

It's a really interesting, and I think complicated concept. In some ways, it's complicated in other ways, I think beautiful in its simplicity. When we talk to patients and this is true for ICU survivors, it's true for long COVID survivors. It's in the ICU that I learned this first. When we talk to patients who survived the icu they'll be quick to say to you you know, I'm alive. But if that's the only thing that I can say, I'm not necessarily that delighted about that. That's what some of them will say. If I am profoundly cognitively impaired if I'm unable to engage in any of the things that I did before, if there are no activities I can pursue, I'm just surviving. And our goal, my goal is to help patients find a way to move beyond surviving to thriving. It's important though that we don't define thriving as the absence of the difficulty that got you wherever you are in the first place.

### (17:34):

Because sometimes that is what it is. Sometimes that brain injury is not completely going away. Sometimes that amputation, obviously, it's not leaving other chronic problems, not going away. So thriving, I think, is finding a way to live a meaningful value-driven life in spite of alongside of, along with whatever challenges you're having to recognize that you're not defined by those difficulties, that you can have a meaningful life as you coexist with them. That's how I think of thriving. And we have beautiful examples in the lives of our patients, patients who are somewhat better, but not all the way, who bear the permanent scars of the difficulties they had, whatever those are. And in Charlie's case, they're the teacher of the year, right? Voted teacher of the year. So tired at work hypervigilant at work because of P T S D sometimes feeling defeated. And yet as Teddy Rho Roosevelt talked about in the arena, engaging, leaning into fear, leaning into difficulty, feeling at the end of the day that they've done meaningful work despite their limitations. That's just one example of thriving. Hmm.

#### Seán Collins (19:01):

It's, it seems like a vigorous approach to living your life that if, if fatigue is an issue for you or if depression is an issue for you, I would think that would be difficult.

# James Jackson Psy.D. (19:16):

I think it is difficult. I'm quite an optimist by nature, and I need to be careful to always reiterate that this isn't a simple thing, right? It's not all rainbows. It's not all unicorns bouncing across a beautiful wildflower covered field. I mean, this is hard work. And it was hard work. It's important to note it was hard work before COVID for people with spinal cord injuries. It's hard work for people with severe bipolar disorder. It's hard work for people with schizophrenia. It's really hard work. And if there's a hill that I would die on, and there aren't many it is that we

need to really believe and, and wrap our ar arms around the idea that even though things are so difficult, we can still find a way to thrive. Now that's gonna look different for different people that sometimes is gonna be accompanied by lapses or relapses.

## (20:23):

In no way will it be linear. But this idea that, that you can do really hard things, that you can live life to the full, again, we might have to redefine that in some cases, but you can find a way to live a full life, even with difficulties. I think it's something that is so important to embrace. What I'm pushing back against thoughtfully, deliberately is the idea that the only way I can be okay is if my long COVID goes away. Right? I don't believe that. We don't wanna reinforce that to our patients. I think that's a very hopeless framing. We want therapeutics. We want the science to expand. We want to cure just as people want to cure for cancer, for Alzheimer's disease, I could go on. We desperately want to cure, but we don't want people to think that the only way they can be okay is if the long COVID is eradicated, because that notion, I think, sets people up to fail. Hmm.

# Seán Collins (21:29):

Jim Jackson, you also tell the story in your book about a patient you named Melanie, whose life as you write, was off the rails, driven by a toxic cocktail of fatigue, cognitive impairment, and depression after COVID. She called you one day and told you that she was thinking about driving her car into a tree just to be done with it, she said, what can you tell me about that patient or that experience of, of trying to help a patient with that framing of their experience?

### James Jackson Psy.D. (22:10):

It's a really interesting story about a really dear woman who has been so brave and courageous. When she decided to get the professional help she needed the professional mental health help she needed she later told me that that was really the first thing she could ever think of, that she had really done for herself. That she was incredibly proud of herself for taking this big step. It was, it was pivotal for her. I think it was transformative for her in the era of stigma that we talked about. Often a visit to a psychiatric hospital would be viewed as a step backwards. I think for her it was clearly a step forwards. And her mental health and emotional functioning has continued to really improve. And I think from that vantage point, she is doing beautifully well as she is beginning to accept some hard things that, that she doesn't necessarily like.

## (23:10):

As she's beginning to set boundaries and prioritize self-care, her physical challenges are remaining. And as is often the case those often become a point of real focus, and they can create significant setbacks. People worry about their physical functioning after COVID. They worry that their symptoms are gonna get worse and, and those worries quite appropriate. Often accelerate depression, they often accelerate anxiety. They can worsen PTs d so her physical remain. But she is bravely leaning into her difficulties in a way that I'm really proud of. I talked to her actually just yesterday, and I'm happy to say she's really doing well.

# Seán Collins (23:57):

Hmm, that's good to hear. You know I'm 60 years old. I grew up with relatives and other people that I knew who had survived polio. And you know, many years later we became aware of something called post Polio syndrome. And it, it occurs to me that that's really, you know, it, it happened, happens with chickenpox and shingles as well, that there's a, there's a follow up complication to an earlier viral infection. It's sort of the nature of some viruses just to hide out and reappear later in different ways. And it occurs to me that with, with SARS Cov two, we have no idea what what may show up 25 years from now or, or 30 years from now in the lives of these people. And I, I say that only to say there's, there's probably real reason to be cautious and fearful in some way of what's coming next. We don't really know what's coming next.

## James Jackson Psy.D. (25:08):

Yeah, I couldn't agree more with that. We don't know what's coming next. We don't know what's coming next with regard to, to worse outcomes. I think we don't necessarily know what's coming next with regard to better outcomes. We see some people get worse. We see some people improve. It's part of the mystery of this. And I think it adds to the complexity. I, I would say one of the skills that we try hard to help foster in our support groups, I'm trying to learn it too, it's not so simple, is living with uncertainty. That's the great challenge. I think the great opportunity too, to learn, to learn, to live with uncertainty, because if that's a nut you can crack then you can handle almost any challenge. But it's not so simple. You know, we regularly see people who are doing better, better, better, better.

## (26:04):

And then much worse we see people who are doing worse, worse, worse than considerably better. You know, these trajectories are highly variable. And those quick turns in the road better or worse they often hook people psychologically, particularly the, the, the worst turns often hook people psychologically, and they add to a lot of fear and anxiety, I think very appropriately. But we try to teach people what in acceptance and commitment therapy, they

call unhooking strategies. Unhooking strategies involve not being captured too much by a change here or a change there. They focus on learning to live in ways that are aligned with your values so that the externals don't affect your internal world as much as they might learning to live, I think above your circumstances. Again, easier said than done, very aspirational, but a lot of our patients are making real progress in this regard.

### Seán Collins (27:12):

Yeah, that's fascinating. I'm talking with Dr. James Jackson, author of "Clearing the Fog" about long C O V I D and and his work with patients at Vanderbilt. Jim, I wanna focus on two chapters that I find maybe as aspirational as the last idea that you talked about. One of them is the only way around is through seeking solutions for mental health issues and finding the courage to pursue them. Tell our audience what you dive into in that chapter.

## James Jackson Psy.D. (27:52):

Sure, glad to. So the only way around is through is a, a quote attributed to a variety of different people. But, but for my purposes, for my part, I, I think it was said by Robert Frost who said so many thoughtful things. Well, the only way around is through, and to me, it signifies this idea that there are no shortcuts. You know, there's no workaround solution. Often that is a better, healthier solution than leaning into things, working through them. And often in the mental health domain in particular, we want to try to take some shortcuts. We want to somehow avoid grieving the profound losses that we've had because grieving is really painful. We want to avoid looking at the friendships that we have and the ways that people are not giving us support during this pandemic. Because if we consider that fully, we might have to end those friendships.

#### (28:57):

There are a lot of things that we wanna avoid. In the book, I talk about a situation that typifies this, I think, where I had an old car, a Mazda 3 23, and one day the check engine light went on, and I didn't really want to deal with it, and I took a note card and I covered the check engine light <laugh>, and I just kept driving, right? I just kept driving. Lo and behold, you know, one, one evening in West Nashville near the Costco, the car broke down at the side of the road. I sold it to a scrap yard the next day with a seized up engine for \$50. So my wife was not very happy with me with that level of a level of avoidance. I didn't want a deal. So part of what we talk about in the chapter, the only way around is through, is that we can wish things away. We can wish the long COVID would go away. We can pray that it would go away, but sometimes the path to freedom is accepting that it is here, at least right now, it's here. And then dealing

with the implications of that. Those implications might be changing your job. They might be changing your situation, they might be making hard choices. But in dealing with the truth about your situation, being able to look at it in all of your fear really clearly often that's where freedom is found.

# Seán Collins (30:28):

I'm embarrassed to tell you that I too had a check engine light in a Mazda go off that I ignored, ignored for a long time. And it met its match on a very steep hill in northern Virginia.

James Jackson Psy.D. (30:46):

Great minds great minds take alike, I guess.

# Seán Collins (30:50):

The second chapter that I want you to sort of talk about in a little bit of detail is actually the next chapter in the book, reframing Your New Normal and the role of acceptance as a pathway to healing.

## James Jackson Psy.D. (31:04):

Yeah, thank you. That was a very personal chapter for me. And, and I'll just share an anecdote about my own life. I talked earlier in the podcast about my O C D. I'm not exactly sure when in my life I developed O C D, but for all intents and purposes, it, it showed its fangs and raised its head somewhere around 2018 or so. And I went to see a psychologist that I had been working with previously for a different issue and, and had no idea exactly what was going on. I was kind of blind to it but I knew there was a problem. And she said, you know, you have O c D and A after some sessions. She said that. And I said, oh, that's fine. <Laugh>, how do we fix it? How do we fix it? And, you know, how do we, how do we burn it down?

### (31:54):

You know, how do we get rid of it? How do we pull it out like a weed? And she said, you know, I don't really think that's how it works. She said, that's not how it works with diabetes. You know, you've got it now, Jim. You've got O C D. And I was really insulted frankly, by that, and I was really angry driven, I think by a little bit of narcissism in the vein of like, other people maybe deal with this, but I, not me, like, I'm going to eat this problem for breakfast. I, I'm not living with O C D. And lo and behold you know, she was right. It, it, it stayed. And it took me about a year to get to the place where I was really willing to consider the idea that I could live, that I could live with this mental illness.

## (32:43):

And I remember really well, I was sitting in the driveway of my house. We have kind of a long, steep driveway. I was sitting at the top of the driveway in this old Buick of, of mine, talking to Jenny, the, the psychologist I remember really well, saying, Jenny, you know, I think after a year I'm finally ready to accept this. What can we do now that I'm ready to accept it? And I think she was breathing a sigh of relief because she thought probably week in, week out, Jim, we're just, we're just spinning the wheels here, right? You're, you're paying me for therapy. We're not making any progress. You're not accepting it. So that, that template, if you will, is what we see with our patients that that embracing, not even embracing, accepting the idea that you have long COVID, that you have ptsd, that you have a brain injury, whatever it might be.

# (33:39):

It's no simple thing. Takes a long time for people to get there. In some cases, not as long, in some cases longer. But when they get there they often find out that even though their life is going to look quite different than they thought it would, and there's grief that goes along with that, it can still look really meaningful. So for instance, we've had patients who were working in really competitive corporate settings, and they developed long COVID, they lost their job they transitioned to home. Maybe they'd take an easier job and they start to grieve their job. And then they say to me, oh my gosh, I, I'm just realizing I hated that job, <laugh>. I didn't want that job. That job was killing me. I hated that job. And with some distance, they're able to see that some of these changes actually might be okay. Yeah. Some of these changes actually could be tolerable, and some of them could be wonderful.

# Seán Collins (34:44):

Yeah, I gotta say from personal experience this all makes sense to me. I, I have I, I experience, I'm the poster child of what I guess is called comorbidities. You know, suddenly I just became sick in all sorts of different ways. I have heart disease, I have diabetes, I have a D H D, adhd, and I have depression. Yep. And you know, at some point it's like, it's like whack-a-mole, right? You know, it's like, how do you, how do you choose which to worry about or try to fix? And then a sort of, I don't know if it's was my monastic training or what, but something kicked in that said, this is, this is life, right? You know, you don't get out of this alive and in fact you don't get out of it without all sorts of different types of losses. And some of those losses are gonna be brought about by medical complications. And, and at the same time, there have been enormous potentials for growth that I've experienced in every one of those conditions. And I'm

aware of growing in, in all four avenues in ways that I think would not have been possible had I not become sick.

James Jackson Psy.D. (36:09):

I, I think it's very true. And I think the challenge is inviting people to consider that. The challenge for me is inviting people to consider that as opposed to trying to convince them of that before they're ready to really hear that. And one thing that I do, it, it, it's, it's very natural now in the support groups and, and also in the individual therapy that I provide for patients. I talk a lot about my own struggles. I mean, I talk a lot about my own O C d. I got a text from a patient yesterday and she said you know, I love the way that you talk about your own quirk and the support group Dr. Jackson, that really makes me feel helped and accepted and, and affirmed. And it's not strategic for me as much as it is me trying to be authentic.

### (36:59):

But I think there is a modeling element where people realize, gosh he's leading the group. He's got his own challenges, you know, some small, some big, and he's managing those in whatever way he can. And, and I can too. And and I think that's really important. The other thing I would say about this that has been true for me, and I think it's been true for some of our other patients, when I developed O C D in my mind, I kind of developed a, a before and after notion of things kind of drew a a bright red line. You know, this was my life before O C d, this was my life after. And and I really nostalgically looked for a time on my life before O c D as if it were perfect. Like I just needed to get back to the garden, so to speak, right?

### (37:55):

I needed to get back to, to this perfect life. And then one day I realized, gosh, your life wasn't perfect <laugh> before O C D, right? You had plenty of challenges before O C D. And that was really helpful for me because I was able to see that it hadn't gone from all good to all bad, if you will. It had gone from one set of challenges to a different set. And when I realized that, that there was no perfect era to go back to, it made me seem like my life wasn't quite as bad by comparison. And, and we remind patients a lot about that, that, that you've got big challenges now. You don't want them, we wish you didn't have them. Yes, your life is different, but try not to imagine that your life was perfect before you developed COVID, because that just isn't the case.

Seán Collins (38:49):

Yeah. I, I remember a psychiatrist in a session once handing me a list of common cognitive distortions that many of us apply to our lives. And I went through the list and it's like, yep, yep. Yeah, exactly. Yep. No, I don't do that. Yep, yep, yep. And realized that the one, the sort of hallmark one for me was catastrophizing, which is sort of, I think what you just described. Yeah. Which was, in the old days, everything was perfect, and now everything is terrible. It's like, no, that's actually a, a, a distortion of reality.

James Jackson Psy.D. (39:32): Exactly.

Seán Collins (39:34):

You came to Long COVID as a pioneer in the research and treatment of post intensive care syndrome there in Nashville. D do you think that experience gave you eyes to see long COVID in ways that others were overlooking?

James Jackson Psy.D. (39:50):

There's no doubt about it. I, I think it was so formative in so many ways. And, and I'm really grateful for those 18 or 19 years working in that space, because I think in some ways it prepared me to work in this space. You know, I saw a couple of things in that space that, that stood out that, that informed the work that I do today. One, I really saw, I learned how gritty and resilient and how tough people could be, you know, seeing people bounce back after, yeah. Being on a ventilator for 60 days, 80 days, you know, losing 80 pounds in the hospital on a 200 pound, 200 pound frame, learning to walk again, I, I, I saw what people could do. And I was pretty convinced even before COVID emerged that people could do really hard things.

(40:44):

And that has shaped my experience. I think, too, I realized that there was this incredible power in community because I had seen it, I had seen it in this community of, of ICU survivors that when they had the support they needed it was Katie Bar theor, you know, they could do really great things. And, and that, that value, that ethos it turns out, has guided so much of the work that I've done in COVID. The situations in some ways are different. Yet there are really important parallels. And I think the big one is this idea that if, if you have a way to make meaning out of something, if you have a way to try to make sense out of something, you can tolerate a lot, right? You can tolerate a lot. You can do hard things. You can live a rich life.

(41:36):

And that's the note, if you will, that I've continued to play pretty consistently. And that's something that I learned working for many years with ICU U survivors. I also, if I could add, I also noted that ICU U survivors were badly neglected by the medical community, especially after they left the ICU. And I was worried, I was very worried that that would happen to our COVID survivors. And sadly, I think it has, you know, I think that's exactly what's happened, and I'm motivated here at Vanderbilt at least, to be part of a cadre of people that are devoted to trying to change that.

## Seán Collins (42:15):

Mm-Hmm. <affirmative>, this pandemic disrupted our lives in, in so many ways. It changed the nature of work for many of us. It, it changed the commercial real estate market pretty drastically. It had an impact on childhood learning and education in general. Do you, do you wanna say anything about what you're hearing from patients about the impact of long COVID beyond healthcare?

## James Jackson Psy.D. (42:47):

Yeah. I think it is dramatic. I've seen the effect on families a lot. We often hear about children, for instance, of our patients with long COVID who have mental health problems that they didn't have before, who have educational problems they didn't have before. We see social patterns, certainly in our long COVID survivors that didn't exist before. Patterns that are insular, often patterns that are fairly avoidant. People not wanting to go to church people not wanting to socialize. So I think there are a lot of social determinants, if you will, in play that are really problematic. I, I, I think we want to respect, I, I don't know if respect is the right word, but, but maybe it is. We wanna respect the impact and the power, if you will, of COVID and long COVID. And that is, that is in contrast with the idea that we remind our patients all the time, let's try hard not to give it too much power. It's changed the world so much, and yet you can decide on some level how much you want, want it to change you. That that's a message that we try hard to push back against. It's in the water, it's everywhere. And yet, let's not let COVID define us. Let's work hard not to let COVID define us, because that's not really a winning strategy at the end of the day.

#### Seán Collins (44:25):

That's Dr. James Jackson. He's the assistant director of the ICU Recovery Center at Vanderbilt and Associate Professor of Medicine at the Vanderbilt University School of Medicine. Dr. Jackson is the director of long-term outcomes at the Critical Illness, brain Dysfunction and

Survivorship Center. His book, "Clearing the Fog" is just out from Little Brown Spark. Jim Jackson, thanks so much for being here. I really have enjoyed our conversation. It's

James Jackson Psy.D. (44:56):

Really been my pleasure. Thanks so much for having me. Look forward to talking to you again.

Seán Collins (45:00):

If you'd like to read an excerpt from Jim Jackson's book, visit our website at HearMeNowPodcast.org

(45:08):

The Hear Me Now. Podcast is a production of the Providence Health System in its family of organizations. It's produced by Scott Acord and Melody Fawcett. We have research help from medical library staff, Carrie Grinstead, Basia Delawska-Elliot, Sarah Viscuso, and Heather Martin. Our theme music was written by Roger Neal. The executive producer is Michael Drummond.

(45:31):

Join us in two weeks for two conversations about heart disease and women. The first with Dr. Lori Tam, a cardiologist about some of the warning signs to pay attention to, and we'll hear from Kris Kleindienst who had a heart attack during a bucket list trip to Paris just a year ago. She'll talk about some of the lifestyle changes that she's made. Best way to be sure not to miss any of these episodes is to subscribe. We have help at HearMeNow,Podcast.org.

(46:05):

I'm Sean Collins. Thanks so much for listening. Be well.