

Ryan Prior Discusses Upcoming Book, *The Long-Haul*

SPEAKERS

Rebecca Handler, Ryan Prior

Date: September 2022

Rebecca Handler

Today I am so excited to be joined [by] none other by Ryan Prior. A lot of people in our ME/CFS community already know who Ryan is, but I'm especially excited to be introducing Ryan today because he is the author of an upcoming book called "The Long Haul". This is a book that really delves into Long COVID and solving the puzzle of this pandemic and how it relates to ME/CFS. So without further ado, I'd love to talk a little bit more about this, Ryan, and I'm wondering if you could first explain, just starting about yourself and your ME/CFS journey, prior to Long COVID.

Ryan Prior

Thank you so much for having me. I've been part of the ME/CFS community for about 15 years now. I came down with a post-infectious illness [on] October 22, 2006. And then I had to drop out of high school. I was a junior in high school at the time, and I was on a hospital homebound program. I had teachers have to come to my house to help teach me throughout my junior year of high school, and ... ultimately we went about 16 different doctors and I was diagnosed with ME/CFS in 2007. I...ultimately graduated from high school and got into college, and throughout my college experience, I was frequently having lots of crashes. I had disability accommodations, and was taking 20 pills a day, and getting a shot once a week, and getting an IV infusion every month. But yeah, things worked out. I eventually graduated and became a journalist. In my journalism career, ME and chronic illness and patient-led research and cutting-edge science innovation have all been themes that I've tried to highlight. I think how ME bubbles up into a larger ecosystem of biomedical research and, you know, changing the future of healthcare have been themes in my career.

Rebecca Handler

That's amazing. You've done so much important advocacy work over the years. So I'm wondering... I know things got a little complicated in 2020 for you. So if you could walk me through what that was like. So you actually experienced COVID, and then Long COVID, yourself. So I'm wondering if you could just tell us more about that experience, what happened and what that was like to navigate that.

Ryan Prior

Yeah, so I remember leaving...being in the midst of... I was covering COVID for CNN, in a variety of roles as a breaking news writer, and then as a features writer, and on the health team for CNN. Especially very early pandemic, knowing I was immune compromised, knowing my body did not fight off

viruses, and I knew a lot of people's bodies didn't fight off viruses very well. I didn't necessarily think I was gonna die from COVID if I got it, but I did think it was going to hit me a lot harder than it would hit everybody else. And I knew that based on the underlying biology of how about 10% of people react to viruses and post infectious or post viral conditions, I knew I was in a danger zone. I did my best throughout 2020, and that was working fortunately for CNN. I was able to work from home throughout that period. All of us were working from home. My last day at the office was the night that President Trump gave a speech from the Oval Office about his response, and I left that night and... did not come back into the office for I think 16 months. I ended up getting COVID, or getting the positive test, on Christmas Eve of 2020.

Rebecca Handler

Oh my god.

Ryan Prior

Yeah, so I got COVID for Christmas. And then I got some Long COVID symptoms for the following two months, and I was on short term disability from my work. And even though we were working from home, I had been hit pretty hard with a lot of the same fatigue and brain fog and post-exertional crash type symptoms that kind of are part of the post-viral picture that we know about from the patient experience, and as indicated in the research. So I think I was not able to go back to work full time or at least to telecommute in until March, I think it was early March of 2021. But...some of that was barely holding together, especially in those those early months, trying to come back into work. But I was...I don't wanna say definitely afraid, but morbidly afraid that this was going to be the virus that took me down again. I had recovered to a degree...about 90% from ME/CFS, from where I had been when I was in high school, but I also knew that I was pretty vulnerable to future crashes, knowing how powerful COVID is as a virus. Yeah, it was very uncertain. So I signed the book deal...probably in February of 2021. And I did not know if I'd be able to write the book because I was so sick.

Rebecca Handler

Yeah, I was just gonna ask. Because that must have been a really difficult... So you decided, so when was that moment for you? When you decided while you're going through this, this is something that I need to write about? This is a book.

Ryan Prior

Yeah...I spoke at the National Association of Science Writers, a panel about how to cover contested illnesses in October of 2020. I...co-moderated a panel with Pam Weintraub, who wrote a notable book about Lyme disease. And I said, "I'm contemplating writing a book about Long COVID, but I figured you're gonna do that." And she said, "No, I don't want to write disease book after disease book". And I now know I also agree with her, having written the disease book, I don't think I'll write another disease book. At least not anytime soon. So Pam said, "Be my guest, I'll let you chat with my agent, and we'll get you set up." And so we put together the proposal in about six weeks. It was about a... 60 or 70 page proposal with...a couple chapters and a marketing outline. And we were shopping that around just after Thanksgiving, and had an offer in early December. So I got COVID a few weeks later, and I remember telling my agent, "Oh, this is gonna be great for the book that I got sick". And she's like, "No, it's not".

And yeah...it's both good and bad. The intention was never to write about my personal story, but there's a chapter in there that details my own experiences.

Rebecca Handler

Oh, interesting. Okay, so this book focuses on the individual experiences and stories of other people that are navigating Long COVID or are going through this, then?

Ryan Prior

Yeah, I'm a science writer by trade. And so I had written a lot of pieces... about science, but really about COVID. And so wearing my CNN reporter hat, the intention was to interview patients and interview scientists and interview doctors and talk about the full international landscape about how this was gonna affect health systems for the next coming decades. I didn't quite have the terminology about what we call now... a mass disabling event, which is millions of people... I understood intuitively, especially in spring of 2020 as this was going on, that this was going to affect a significant number of patients, and in ways that the ME/CFS community understood that the rest of the world didn't. And we didn't have the word Long COVID or long hauler, or...mass disabling event, but I think a lot of us, Linda Tannenbaum and OMF included, felt this was something very bad that was on the horizon. So my mission as a journalist was to cover the human and scientific and medical and political and societal and economic costs of it, but really to tell it through a lens of a handful of characters that I thought were like the human heartbeat at the center of this pandemic, which is really the most world-changing event of the 21st century. So I felt like my whole life had set me up to write this. So... my own patient experience, which is included in the second half of the book, a little bit, was an added bonus. That virus gave me my own run for my money,

Rebecca Handler

Right? It is so interesting, because I think you're right that people with ME/CFS, we kind of had this unique foresight into what might happen, having lived through these personal disabling events. So many of us... we had this viral trigger, this viral onset. I even remember that in...I think it was April, hearing about all of these people getting sick. It was April 2020, you know, a few weeks later and realizing, "Wow, this is actually...I wonder what the recovery process is going to be like", and I actually don't remember the first time I heard the word Long COVID. But I do know, it was interesting, because I remember reading that this was a term that was really defined on social media through patients themselves that were describing this. And I think that is just so interesting that it was just a collective of people coming together and saying, "What is going on? ...We're done with this acute phase, but yet we're still living in this limbo, and nobody seems to have answers". And people on the ME/CFS side of that were saying, "Oh, this sounds a little familiar, doesn't it?"

Ryan Prior

It can be traumatizing for anybody who's been through this horrific event of ME/CFS who's felt like they've been erased from society, that their sense of selfhood has been erased, that they're being gaslit. And they have a disease that the whole of western science appears to have no real footing for. I do believe that molecular biology is going to solve ME/CFS. But at least when your initial entry point is that every doctor you speak to isn't gonna understand it...it's really deeply distressing for every ME patient, I think, to know that what they've gone through is going to be a psychological journey for each

other post-viral patient...all of these other people are going to have their own life cave in, and they're going to have to completely reorient their understanding of what it means to be a human. So that is what I was personally going through as...my own lens for viewing the pandemic. Disabled people or chronically ill, or people with ME, have a form of wisdom that needs to be projected far and wide, and you need to have a seat at the table as decisions are being made. A core thing that stuck out to me, especially as a CNN reporter covering it in February 2020, was the number of White House officials would make comments that would say something to the effect of, "For the vast majority of us, we have nothing to be afraid of. A few people who are immune compromised may die". And I remember someone tweeting and saying, "You know, just as an FYI to the powers that be, those of us who are immune-compromised, we can hear you when you say those words. So immune-compromised people or disabled people need to be part of the "We" and I'll preach...

Rebecca Handler

Yes, I think that's so important. I think that's still a common theme that I see even two years post-pandemic, as we get back to normal. There is still this, "Oh well, COVID is out here. But we're resuming a sense of normalcy, except for those who are immunocompromised", and it's almost this picture of us being...people that are chronically ill being the Other, as separate from society, which creates even more divide and invalidation and it is, at the very heart of it, emotionally traumatizing to go through that. To feel left out and totally unprotected by our society and our governments and our healthcare system. So I think you're picking up on that in the book. I do remember seeing that, especially in the beginning that, "This virus will not kill you...unless...you're immunocompromised, and then the second thing that I remember thinking is, "Okay, well, maybe it won't kill you, but there is this whole...death isn't the only thing that could happen after someone gets a virus or infection. There's this whole other world where some people just don't recover, and that wasn't really being communicated. It was, "Oh,...you know, you probably won't die". Okay. Well, that's leaving this whole conversation out that [is] what happens to everyone else that...they don't die, but they also don't recover fully?

Ryan Prior

One way that I would advocate about how we might think about future pandemics, and I do want to make sure that this book is used as an example for how to cover pandemics in the future, is that we, as a society, frequently talked about this idea of a case fatality rate. And so people would make an argument that, you know, less than 1% of the people are going to die. We don't need to do lock downs, and this and this, and this. But a very easy way to frame this is, you know, not just case fatality rate, but... a case disability rate. And that's gonna be about 10...depending on what what set of numbers you use, and I'll use easy numbers and say, that could be about 10 times higher of disabling effects versus the fatal effect. And it makes sense that anything... the philosopher Nietzsche says, "Whatever doesn't kill you makes you stronger". It's also true that whatever doesn't kill you could simply disable you. And that is important...with any other...bad thing that occurred. Like, if you go into war, if you don't get killed, you might get maimed, you might come out with PTSD or a long term injury. And we know that with most soldiers coming back from Iraq, that there's fewer deaths than Vietnam, but there's a lot more disability. The same thing is true with COVID, that there might not be as many deaths that have occurred in certain other viral diseases, but as a society, we need to frame, "What does it look like to take care of people who are disabled from these past tragedies?"

Rebecca Handler

Absolutely. It's so important, that the impact is just enormous. We don't know. The economic impact is one number that I see being thrown around a lot or being talked about a lot. We just reached, I believe, it was over a million people just in the United States that are now out of work...due to this mass disabling event. And that's just one small aspect of it. And I do think....it's almost a second pandemic that rages on as COVID exists. It just...continues to create this long term disablement. And I'm curious, just about like, while you were navigating, while you were writing, what did you find to be some of the biggest challenges in getting this story out and communicating all of these points while you were writing?

Ryan Prior

I think it was fairly easy or intuitive for me to...most of my life as a writer was reaching out...prior to the book and prior to the pandemic, was reaching out to experts, reaching out to sources, getting them on the phone, getting the piece done, edited, fact checked, and published ahead of your deadline. And that was equally true during the pandemic, if not more. Any scientist I reached out to who was actively working on COVID felt a sense of mission in a way that no other scientists that I had encountered had. Naturally so like we were living in an event that, by some respects, may have threatened the future of humanity, so getting the pandemic figured out, was the most motivating thing that most scientists are gonna go through in their lifetime. So I loved getting to speak to scientists throughout my CNN reporting for my day job. And then when I pivoted over into doing the book full time, I met some incredible people. One of the clinicians I'll highlight who I think deserves a lot of credit is Dr. David Putrino, who runs the Mount Sinai post-COVID clinic. He has an incredible background as a PhD in Computational Science. He's also a physical therapist. He understands the patient-centered side of doing high tech research. I'll say that in a little snapshot there, but there's a lot more to it. And he's become really one of the...in my opinion was probably the most interesting person to interview, and I think he has a unique insight into how this is all unfolding and the ways that a lot of doctors are getting Long COVID wrong. And partly because they're not actually seeing the patient.

Ryan Prior

And this really comes down to a very basic concept which the most well-known journalist who covered ME/CFS in the 80s and 90s - Hillary Johnson, who wrote a book "Osler's Web" - she talks about Sir William Osler, who was the Dean of medical education, so to speak. He was the most famous medical scholar of the 19th century, and he argues that, "Listen to the patient, and he or she will tell you what the disease is". And what I see Dr. Putrino doing in the Mount Sinai clinic in the 21st century, during this global health crisis, is very similar. I mean, he's got all the degrees to back it up. But it's a patient-centered approach. And that's where most of medicine, I think, is going to improve when we do a patient-centered approach. And in the coming era, which molecular biology is helping to inaugurate, is one in which precision medicine and personalized medicine will become the norm for a much larger number of people. And so taking that personalized approach to each individual Long COVID patient is one of the first things...I would say...that should be blatantly obvious. And that's been...if you're asking the question of what's been the hardest thing to communicate, I think it's the most obvious thing, and has been one of the hardest things to get across.

Rebecca Handler

So...that brings me to another great question, I think. To follow up on what you're saying is, "What do reporters get right about Long COVID when they report it, and what do they get wrong?" And I think you answered that a little bit by saying, "...This lack of patient centered approach to looking at this problem and looking at the patients." What do you think on the other end of that, when when looking back at all of the reports, and how we communicate about Long COVID? What would you say we're getting right when we communicate this story in media?

Ryan Prior

The Body Politic, which is one of the predominant online support groups for people with Long COVID talks about being patient-centered and historically informed. So the historically informed part is important. Part of that is being for being informed by how previous viral pandemics. Things like this happened with the 1918 flu. We had mass disabling events following poliovirus. Mass-disabling event following HIV, which is AIDS. It makes sense that there's going to be this type of illness following a virus. That's part of it. There's also a social justice component where you need to frame these...I think the disability rights movement needs to be framed in a similar light to how women's rights or civil rights or gay rights is framed, that this is a huge group of people whose whose human rights matter, which are not necessarily being framed or not being elevated. There's a big, pretty major mistake that I think is obvious...I hate to see reporters do this and some of them still do, you know, talking about this as like these 'puzzling symptoms, this befuddling, confusing, strange new illness. Especially in the headlines....I'm doing a piece for a magazine at the moment about what... it literally is 'What reporters get wrong when they when they write about disability'. And I'll say what reporters get wrong when they write about Long COVID is calling this a new disease. It's not. Calling it confusing. It's not as confusing once you actually talk to experts. And then one of the things is... an over-emphasis on talking to clinicians, particularly clinicians who don't see Long COVID patients. And you'll get the wrong information if you do that. And a lot of reporters find that when you call up patients, you get...in my opinion, the quality of information was sometimes 10 times better if I talk to a patient, versus talking to certain clinicians.

Ryan Prior

The human desperation fuels innovation, which as you know, necessity is the mother of invention. People who need the system to work better are going to be actively figuring out ways to make it work better. And so that's why the Patient-Led Research Collaborative is another group that I think is of historic importance for centering the patient experience. And my role as a reporter is - and has been, and always will be -to reach out to the best people to figure out what's going on. And it was clear if...I was just trying to talk to who was the smartest, and in my opinion, it was Hannah Davis, who is the head of the Patient-Led Research Collaborative. She was putting out the best information. And she's collating all the science coming out from all over the world, and judging it, and elevating what's good and what's new. And there's people that I've spoken to who do like these really interesting...health care social media analytics. You can draw these webs off the Long COVID hashtag, of who's using Long COVID hashtag, who's most influential. I had a guy draw this for me who worked for a place called Simpler Analytics, and Hannah Davis is the center of the web. And that was my intuition, following the story. So that was a key character in the book. Which is to say that certain people from the CDC ...well, I mean there's great people at NIH and great people at CDC, but there wasn't anybody who was quite at that level. And there's an interesting quote in the book where someone refers to Hannah Davis as

the Larry Kramer of Long COVID. It was just funny, as I mentioned that to Hannah, and she's like, "I don't know who that [is]. Who's Larry Kramer?" And so we explain this in the book that he was kind of the predominant AIDS activist as part of...a founder of ACT UP.

Rebecca Handler

Social media, I will say, plays a very unique role in COVID, and how we've come to understand this experience, especially the patient experience. Because unlike, say, the 1918s, the Spanish Influenza, and even in the 80s, when we had HIV, we never really had this two-way communication between journalists and between patients. And now we're able to use platforms like Twitter to really connect and to have this dialogue...For example, I think one of the interesting things is how the Long COVID community immediately connected to the ME/CFS community. So people were talking about their experiences and they were finding each other through, for example, these hashtags. And people with ME/CFS, say, 10 years down the road of them having an illness, were able to connect with people that were newly diagnosed with Long COVID [and] were trying to figure out what was going on with them. And they were able to point them in the right direction. But had we not had this kind of digital town square, so to speak, of these people connecting and sharing their patient experience very vocally, I think that would have gotten buried. And I think that's also why maybe...in my opinion, I think that's helped us to usher our way into this more patient-centered era of medicine. This personalized approach. Because I think you're right, it's just so important to...for example, when we talk about medical education, we could talk about it in forms of statistics, and how many people get sick - but those are numbers. So that's why I'm personally a big proponent of case studies and having patients connect with doctors personally. So I think you make such a great point about this connection.

Ryan Prior

It's so much easier to tell it through the lens of...a narrative arc. You know, a person living a life, got a virus, here's what happens, dot, dot, dot, dot, dot. If you dress that up in epidemiological reports, you lose the human center of it, which is you lose the narrative thread, and then it doesn't really hold together as a story. And humans process the world through stories....Writing the book was keying in on telling us to like you know...I don't think I was trying to do anything profound from like a computational science standpoint. I was really just trying to keep track of what happened and... characters are a way to do that. And a couple key characters, one is Alison Sbrana who was an ME/CFS patient going back to about 2014. She joined the Body Politic group. She did not have COVID, but she knew that the people in Body Politic were probably going to be experiencing ME/CFS or something along those lines, and she jumped in there, demanded to be to be brought in, and her viewpoint, which is the ME/CFS viewpoint, came to permeate that group. And she played a huge role in helping inform...helping make sure that Body Politic was historically-informed, basically. And then Body Politic and other groups were very influential in the medium. Another key character, Elisa Perrigo, who is an Italian archaeologist, she coined the term Long COVID.

Rebecca Handler

Oh, really?

Ryan Prior

Yeah, so she uses this hashtag in English, which is...the language is important. Because she makes a...somewhat stray comment, I think in spring of 2020, saying, "This...so-called Long COVID kind of looks like this is happening." And that's where...it sprouts from there. You've got some different hashtags and some different languages. In Spanish, it was hashtag COVID persistente. And then in French, it was 'Après Jour 20', which is after day 20, having symptoms after day 20. And those were catchy, but Long COVID was the catchiest. And I think it's helpful that it was in English. Elisa communicates in Italian and in English, but getting it to resonate across the English-speaking world was particularly meaningful, I think, in this capacity. And then at least, I will strongly credit her for staying on it for a very long time, and never, never stopped beating the drum that this was the patient created term. It's also, from a marketing standpoint, I think it's the catchiest. I don't quite say it's poetic, but it's easy to say. The NIH created the term, or the government created the term, Post Acute Sequelae of COVID. There is some virtue to that for being scientifically descriptive, but it buries the lead. Also, Long COVID is a word that regular human beings understand.

Rebecca Handler

Right? That's what I like.... I think that's what's so unique about calling it that is it's...very relatable immediately. You're able to understand, you know, long, Long COVID. So it's just like, as your book title, "The Long Haul", that's immediately the imagery that you get in your head, I think, is that you're in it for the long haul. And then, of course, I remember that back in early 2021, it was just the long haulers, that's what really emerged. And I remember seeing that. And I know that people with ME/CFS immediately said, "Okay, we've also been long haulers for years and years." And I do think you're right, that this is... there's something extremely unique about this being a patient-coined term. And it's permeated into the science community as well, because you have doctors that now say Long COVID. Although there is PASC, the post-acute COVID sequelae, we have that as well, but now you're seeing even the medical community adopting Long COVID. And I think that language was important, because in a way, it was almost like the medical community joining hands with the patient community there, and accepting the term for it and understanding it. And that's something that we previously perhaps haven't even gotten that far with other post viral illnesses,

Ryan Prior

It's especially important, just because the number of healthcare workers who got COVID, and then therefore get Long COVID. There isn't this sort of weird separation between patient and doctor because a lot of the doctors are patients, a lot of patients are doctors. Both identities exist inside of the same person. There's an important role of being a patient-researcher or a researcher-patient. If someone's only a patient or only a researcher, you don't get that same amplification of effort. So that's been interesting. And the term you know, we've had a name game in this community for a long time about Chronic Fatigue Syndrome versus Myalgic Encephalomyelitis or ME/CFS. No one seems to be able to win. There's no good answer on that question. So yeah, Long COVID and long hauler are great answers to the question. And I think it's been...I'll reference a couple of different ME/CFS advocates in the book and call them an H1N1 long hauler or an Epstein Barr long hauler. And I think that there's real value in that language. I find it very folksy and poetic. And some people say it sounds like a country song. I don't think it's a bad thing. And that sounds good.

Rebecca Handler

Yeah, I agree.

Ryan Prior

That's maybe part of the appeal. And the word long hauler comes from one of the early advocates who was willing to go get tested for COVID. And, let me make sure I get her name right, Amy Watson, she decides to put on her lucky long haul trucker cap to go get tested. So interestingly, the long haul trucking community feels that they have a place here in history.

Rebecca Handler

Oh, interesting!

Ryan Prior

There's an interesting article written on a place called Overdrive.com, which was a site for long haul trucking news. They were pretty happy about the fact that their word is really resonant around the world.

Rebecca Handler

I mean, it really does, because it's a journey. And I think people just go through this whole...I mean, it's not just a literal journey of going from doctor to doctor, but also an intensely emotional journey, where your identity is just totally challenged and reshaped by chronic illness. I don't know if that's something that you were able to experience while going through Long COVID. Or maybe a theme in your book is exploring identity and illness?

Ryan Prior

Thematically? Yeah. It's essentially the most important question that we strive to answer for ourselves as human beings is who we are. I know in +-own life, I used to say that the entirety of my existence pivoted on a certain day, October 22, 2006, when I got this illness and I came home from school and slept for 16 hours. And I think that's more or less the case with long haulers I interviewed. Most people were pretty aware, you know, March 17, 2020, I got a light cough. And then that was it, I've never been the same since. And I've heard that narrative for years with ME/CFS patients. So it was pretty clear, just knowing what to look for. A doctor might call that a patient history, you know, I call that a story. You look for those narrative threads and those plot points. The pivotal plot point is the moment of viral onset. The moment of viral onset, you know, as an English major, I see that as the insinuating moment of the plot. That's where the entire story pivots, that's where it gets interesting. And that will be like the first page of a novel. And well, the first page of my book is technically about referencing that Oval Office speech that Trump was giving.

Rebecca Handler

That really just put it into motion. Yeah, that was your moment when you're when you realized, would you say?

Ryan Prior

Yeah. So even though all of my life had led up to this moment of knowing that this might happen, then the awareness to see my own narrative voice as a character in the book, I have the moment of

realization. You know, during the Anderson Cooper 360 show watching President Trump speak. And then getting a sense that...the world is turning, and then my particular frame, and the world is also turning. And my mission in life, therefore, is going to be to tell a story. I had produced a documentary film about this disease before this, but ultimately, I actually wanted to be an author, more so than a film director. So this was my opportunity to become an author. I could see how things were gonna start coming into focus.

Rebecca Handler

That's amazing. And what was the most surprising thing that you learned or discovered through writing this?

Ryan Prior

I think part of it is that I learned a lot of things about the publishing industry and about journalism and about the political world. And I think I learned something about humanity that I...I think that the world is a bit more divisive than I realized. And I think that that manifests in a couple of ways in which you would think that a pandemic like this would bring us together rather than separate us. So that that was one major sad but true learning point for me. And then another thing is that I believed that the best researchers were going to immediately get funding to study Long COVID. And that it would be very clear that there was a steady progression from getting the virus, to getting long-term symptoms, to getting what might be a post-infectious, disabling disease. There's been a huge amount of progress, so I don't want to discount that. And there's been a lot of people who have changed...a lot of hearts and minds have gotten changed. But I've been surprised that some people, some experts, have dug in their heels and not been able to see long term before it really is.

Ryan Prior

And I'll borrow a phrase that my colleague, Kim Knackstedt, who was the former disability advisor for the Biden White House. She frequently talks about the need to see this through the lens of disability, which is different from seeing it through the lens of infectious disease, or through the lens of psychology, for that matter. Seeing it through the lens of disability means that this isn't an illness that goes away. This is an illness that's permanent. That's the basic idea of what disability means. And when you see it through that lens, people have a certain set of human rights that are enshrined by law, the Americans with Disabilities Act and other human rights structures in other countries. But you're operating under the understanding that the status quo has changed, and unless you act urgently and quickly, the status quo will stay that you'll be sick. I think that that's helpful. And so patients, I think...it dawns on patients earlier than it will probably dawn on a lot of doctors, but that's useful for clinicians who are working with a patient is that they need to see this as something that's more often...the inertia of the illness is that it's going to stay rather than go.

Rebecca Handler

Exactly. And I think that's one of the amazing things that your book had helped bring to light. And hopefully, not only just for patients to resonate around the world and to understand the journey better, but also to expose this narrative for the general public, for doctors, for healthcare providers to understand things with that disability lens. And that patient-centric narrative.

Rebecca Handler

Ryan's book is now available for pre-ordering on Amazon. So we'll share the link. Ryan's book comes out on November 15th. And we are so excited to be able to share this interview and more about your story, Ryan, and thank you so much.

Ryan Prior

Thank you so much for having me.