Transcript: Disparaging language in patient records

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Dr. Nicole: Welcome back to bold conversations. Our special series through the immune deficiency foundation where we explore topics related to health and equities. And today, we are talking about stigmatizing language in the clinical record. And I'm so excited to have my guest today. Her name is Ilana Jacqueline.
Ilana is a two time author. She is a speaker, a patient advocate health care consultant and content creator. And Ilana has spent more than fifteen years working on both sides of the healthcare conversation, helping patients navigate the system, while also keeping the industry better informed and better able to really earn the trust of the people that it serves. We were talking before we hit record. There's a lot of alignment in the work that Ilana and I do, and I'm just so thrilled and excited for her to be able to share her unique expertise and lived experiences.
So, Ilana, thank you so much for joining us on bold conversations today.

Ilana Jacqueline: Thank you so much for having me. I'm so excited to be talking to you. I I did some reading up on all your work and your work even deficiency foundation, your programs to help patients navigate their health care, and I agree there's so much alignment here.

Dr. Nicole: Thank you. I really appreciate that. Before we get into your journey, I guess, I wanted to just kind of set the stage for the listeners, for the audience. Because in case you're not aware and you're like, wait, stigmatizing language, all of you know that when you're in the room, when you're talking to nurses and doc and other health care professionals, there is a record that is generated. And it would be nice if everything in the record was accurate.
That's actually not true. And it would also be nice if everything in that record was purely objective data based on your clinical symptoms, based on your laboratory results and things of that nature. But we are all human. And as we've talked about on prior episodes of bold conversations, we all have bias, literally every single one of us. And and interesting ways our biases make their ways into when I say our, I'm saying healthcare professionals. The biases of healthcare providers, it makes its way into the medical records. In the form of stigmatizing language. And so if the healthcare provider has a particular opinion or a particular bias or sometimes if there's a challenging interaction, often there are elements of that encounter that make their way into the record. And so things like describing patients and families as being difficult, or questioning, you know, the validity of someone's symptoms. These things end up in medical records, and it's a very well studied phenomenon.

And the reason that we're talking about on a bold conversation is not only is this important, but it disproportionately impacts certain patient populations. So with that, Ilana, I know that a lot of your work has to do with medical gaslighting and bridging this gap between patients and families and healthcare providers. How did you come to this work? We all have a story behind what we do professionally. So what in your own life led you to this work that you do now?

Ilana Jacqueline: Well, it's definitely a long story, but I think I just wanna say too that I'm so excited to be doing a deep dive on everything you just described. Because it's so it's so important. It's such a big part of my story as well. I was I was not diagnosed until I was nineteen years old, and I had been living with some form of a chronic illness, constant infections, constant doctor appointments, antibiotics, hospitalizations, and going to doctors and and begging, really, first of course, it was my mother who was the advocate for me since I was a kid. And then as I grew up, I was was starting to become my own advocate and I was going to my own appointments and trying to figure out, you know, why am I different?

Why am I the only kid in class that when they go to school and they catch a sore throat, they're out of school for the next three, four weeks. And other kids come to school, they get sick and they're back in two, three days. Didn't really make sense to me and didn't really make sense to my parents, but we kept getting the same kind of dismissal from doctors, oh, you know, you're just a sickly kid and sometimes it just is this way. And are you sure you're taking all your antibiotics? Which, of course, I was taking all my antibiotics.

Who wants to be sick all the time? But that is a big part of my story was was growing up undiagnosed, and and all of the language that was used around that to describe me in my medical records. And to describe me in the exam room, it's very it's very disheartening, but it also kind of cuts straight through you when you hear the language that's, like, you know, are you sure you are you sure you're not just faking this because you wanna get out of school or, you know, come on, buck up. Like, don't don't be you know, I I don't know if the word weak exactly was used, but that was definitely the implication. So when I was nineteen years old, I was a college student.

I had spent the last year of my life in bed completely debilitated by mono. And I kind of decided, well, this is it. This is my year. I'm gonna spend the entire year. I'm out of pediatric care.

I'm an adult now, and I'm gonna figure out what's wrong with me. And so I spent that whole year just going to different specialists and trying to figure it out. And ultimately, I ended up with an infectious disease doctor who took a look at all the blood work and all the medical records that I had brought with me and all of the notes that came along with that. And he was able to look at it with fresh eyes and do the right tests on me and eventually diagnose

me with primary immune deficiency disease. And that is my origin story of how I was finally diagnosed.
And and once I was diagnosed too, I think this is also a really important part of my story. It took me another ten years to find a doctor who understood the disease ball enough to treat me. And so I wasn't diagnosed until I was nineteen, and I wasn't really treated with the right regimen for immune deficiency until I was thirty years old. And now I'm gosh. And now I'm thirty six years old, and I am been on treatment subcutaneous immunoglobulin therapy for the last six years.
And and I'm doing great. And, you know, so much of my story is wishing that I could go back in time and just whisper those words to myself of like, hey, get tested for this and and don't listen to that doctor, but I can't. I can't go back in time. But what I can do is I can advocate and and reach people at that early point in their lives. Where they're just starting down this road of trying to figure out why am I so different and be able to give them those resources to understand their body and to advocate so that they can get their diagnosis.

Dr. Nicole: I wanna thank you for sharing that. And I have to say before I say anything else, I am so sorry that you suffered, that you endured. And I can't even imagine you're just trying to be well, get well, stay well, all the energy it takes for that. And then on top of that, to have to advocate for yourself as a nineteen year old and talk to people and get people to listen to you and understand you and stop dismissing you, So I'm sorry that you went through that. And I'm very thankful that now the other side of it, you are using all of those horrible experiences to empower and advocate for others.
So thank you.

Ilana Jacqueline: Thank you. Yeah. I think this is it ended up being a a wonderful thing for me in the end because I do love my work in advocacy. I've had so many wonderful opportunities working in the nonprofit space than working with biotechs. Eventually consulting.
And then I also have my two books now that are reaching patients. And this is, you know, a wonderful road for me to be on now as I as I am, you know, getting to reap all the benefits of my treatment and getting to live my life healthy for the first time.

Dr. Nicole: That's awesome. I wanna talk about the why. And you and I may not have all of the answers. And like I mentioned in the intro, this has been studied to some extent, as a physician myself and also as a former caregiver and somebody who's been in medical spaces as a daughter and has witnessed some pretty horrific things. I bring this kind of duality to this conversation because I know as a physician that for the most part, there's always bad players in every industry.
But for the most part, doctors are good people with good hearts who entered this field to

help. And at the same time, what just happened to you is not unique. And there are other patients and families who have suffered similarly. And so a listener may be wondering, you know, why would a doctor or nurse or anybody in health care say something or even maybe worse, write something, like document something in a patient's chart that reflects their own personal bias about whether they're faking or whether their symptoms are real or to your point, whether you're trying to get out of school, you know, by faking illness, which is just ridiculous. But in your opinion and from your vantage point, why do you believe that healthcare providers make these disparaging comments in the medical record?

Ilana Jacqueline: Well, I definitely agree with you. I have so many wonderful doctors in my life that it's hard to wrap your head around, you know, the idea that that any of this is attributed to malice. It just doesn't really work that way. It's not really that doctors wake up in the morning and drink a cup of coffee and say, oh, I'm gonna inflict some trauma on some patients this morning. That's really not the the the reason why.
But there are many reasons why, and this was something that I really wanted to do a deep dive into while I was writing medical gaslighting, and I was interviewing different doctors and different people within the healthcare system and patients themselves, and just going back to the research, and there is a handful of reasons that I think really do explain everything. You know, there's an inherited misinformation, and that's, you know, the centuries of of theories about women's bodies, kind of like masquerading as science, and this goes all the way back to hippocrates and the wandering womb and it's really anyone who has not done the deep dive on, you know, just women's health way, way back. It's so fascinating and I highly recommend going and and and researching that. I do I I did write a bit about it in my book, but, I mean, I could go on about that for hours, but I won't. And then, you know, it could that kind of let us into what we have now, which is a real knowledge gap. You know, medicine was was built around the reference man, which is like, you know, science's definition of, like, an average human being, which was a man and not a woman. And wait a certain amount had a specific type of muscle mass, you know, it was one type of person that we wrapped all this research around and it excluded women. And because of that, up until nineteen ninety three, we were not including women and sex as a biological variable that just wasn't the NIH policy until two thousand and seventeen. And so this huge knowledge gap yeah. This is really something that that shaped a lot of the misunderstandings that that prevent collaboration between men and women because doctors are relying on this data, and this this data is accurate for men, but it's not always accurate for women.
And so without that knowledge, it's hard to to be able to definitively say, hey, this is what's wrong. So so definitely the knowledge gap And then they're just the limits of of what what medicine knows. And there's so much that we don't know, so much that we're

understanding now. You know, we're I'd like to say that we're in a more positive space. I love seeing what's going on in FEMTECH.
And the money that is now flowing into women's health, and I feel like over optimistically, but over the next ten years, I think we are going to just leaps and bounds, understand women's health so much better And I I really do believe that that will have a massive impact on the amount of medical gaslighting that happens because the more information, the even more facts that you have, the harder it is to to insert a bias. That that doesn't really help. And you know, then there are there are other things. There's burnout, physician burnout, you know, we went through COVID, and that's and that's really kind of for me where my heart just, you know, while while I was writing medical gas, I think my heart was like, I know this can't be malice. I know it can't all be malice because these healthcare workers, what they went through, what they continue to go through, to save lives.
It's just it's not it's not it just can't be from from a place of anger or or a place of not wanting to help. I think they really do want to help. So burn out the volume of patients that doctors are seeing every day. They're not getting a chance to to do the kind of work of that they that they want to do. Yeah.
And and so and so it's it's a matter of of not really getting a chance to to to see patients the way that they they want to see them. And then there's always implicit bias. So, you know, there are and we'll dive into that a little bit more. I'm sure, you know, we're you you kinda get typecast before you even open your mouth. And that's, you know, weight, race, age, when your accent, your tax bracket, so many things that go into shaping that that first opinion about a patient.
And yeah. So those are those are some of the the high level reasons that I think were seeing this.

Dr. Nicole: Yeah. Thank you so much for sharing those. All of them just, you know, they really resonate with my own personal and professional experiences and stories I've heard from friends and family members and clients that I've worked with. This knowledge gap, I wanna circle back to that one in particular for a moment because maybe I can help the listeners understand again as a physician. There's there's something that happens to you when you go through the medical education process and because the human body is so complex, and like you said, Ilana, not all of us are built the same way.
And I remember in medical school learning about the seventy kilogram white male. Like, that was kind of like the prototype. Right? Mhmm. And, of course, many of us don't fit that category, but something happens psychologically where, one, you finish school kind of, you know that you don't know everything, but then you also are probably a little overly confident about what you do know.
And then also, I think for some, there's this level of there's a vulnerability that is required as

a physician, as a healthcare provider, to say you don't know. And not to put myself on a pedestal because I have lots of faults, but that's one thing I always embraced not knowing. I always was, you know, very comfortable telling a mom or a dad as a pediatrician. Hey, I'm not really sure. What's wrong with your son, your daughter?
But I'm gonna figure it out, you know, and tell me more. But I noticed, like, that's not something that's pretty common. And so I think that going back to this knowledge gap, unfortunately, what happens sometimes when a patient like yourself has a complex condition that doesn't fit into these little boxes, these little algorithms that we were taught. Right? You know, we're given these These are the ten signs, these are the five symptoms, this is what this rash looks like.
When patients don't fit the textbook, there is it's almost like an assault on ego, and I think that many physicians, if they can't figure it out, then then you have to be the wrong one. You know what I mean? It's like, if you don't fit into this box, if you don't fit into this script that I was taught in medical school, in residency, in fellowship, then somehow you must be the one that's wrong. It's not that I've never heard of this thing or I'm not recalling what this could be. And that's a scary thing, you know.
But

Ilana Jacqueline: I'm just gonna say it out loud. It's scary. Think about it in the context of any job. Here you've been taught your your trade, your skill, and and suddenly a problem comes, and it's not anything that you've been taught, and it's not responding to any of the solutions that you have. It's a very frustrating, you know, situation to have no matter what your profession is.

Dr. Nicole: Yeah. And so the sad part in medicine is that that uncertainty instead of it fueling a desire to, like, look, I need to do more research. I need I need to figure this out, sometimes it turns into, well, this patient must not be telling me the truth or, you know, they should have gotten better. So they must not be taking the medication, the way it was prescribed. So, yeah, I I appreciate you sharing all of those.
You know, I I definitely have witnessed stigmatizing language verbally, you know, unfortunately as part of handoffs where maybe one of my colleagues was on call the night before. Maybe they did have, you know, an encounter with a with a family or with a patient that didn't go as planned. And then, you know, things are said about patients, things are said about families. And sometimes it may be very light. Like, you know, oh, watch out for, you know, this one's spouse or this one's parent or go in this room or, you know, that kind of thing.
But they're they're trans deferring this knowledge of a bad experience that they had. And I've seen how that can influence the entire team, you know, where it it people go in now guard it. And I've also seen where people have patients and families that have been

described as quote unquote difficult, high maintenance, all the words that we sometimes use. I go in and it's like, oh, like this person is lovely. And so again, not it's not to say that I've never had bad experiences with patients, but I think what I'm really trying to say is it's bad enough when we have these verbal exchanges where language characteristics, things are being described.
You know, verbally. But it's even worse in my opinion when it ends up in a medical record that is now, like, a permanent thing, a permanent representation. What are your thoughts about that? Like, when these thoughts, these biases, these feelings are now part of a document that follows the patient from doctor to doctor, from hospital to hospital.

Ilana Jacqueline: Yeah. I think when that happens, like, this is the this is the part where we need to lock in. Because this is really when it comes to medical gaslighting, when it comes to misrepresentation as a patient, everything lives in these medical records, and it's so so important that you know what's going on in your medical records. Because talk evaporates, you know, just like you said, you know, conversations in the hallway before you walk in, things that are said that are, again, off the record, it evaporates, but documentation compounds. And that is it could be a good thing.
It can be a very, very bad thing. Now, the the notes that we have for a medical record, you know, you leave the doctor's office, you get a a a ding on your phone. It says, hey, new office summary, new office visit summary, new clinical notes. So many people so many people go into their phone, see that, and just completely ignore it. And I think the number one advice that I wanna give is don't ignore that text message.
Go into your my chart app or whatever your portal is, and read it. Read it. Bottom top to bottom, I mean, you you really should see and compare, hey, did what happen in that appointment from my point of view make it into the medical records? Because that note becomes the official version of what happened in that room, no matter what actually happened in that room. So and and that medical note, you know, it's it's a note.
It's passed around to all your other doctors. It follows you everywhere you go. And there are so many different types of wordings that are really big red flags. And what can happen is that, you know, you're misinterpreted in that document. And then, let's say, you have an emergency and you end up in the that last note follows you in.
And if that note says, oh, you know, they're just, you know, kind of a hypochondriac, and you're coming into the with a stiff neck and and, you know, a bad fever, you're you might be overlooked for meningitis because you're now a hypochondriac according to the record.
So, yeah, I think it's I think it's very important that patients are alerts, are aware, and are reading what is being said about them in those records.

Dr. Nicole: Absolutely. Thank you for sharing that. Because then you're right. In this day and age, you know, with portals and everything like that, we get the emails, we get the text

messages, and most people like you said, they don't they don't open it. And even if they were to open it, I don't think they we don't recognize often patients and families don't recognize that they do have some power so to speak.
You know, they're they they have the ability to read it and to recognize that it may not be accurate and then to do something about that. I I don't think we all appreciate that we are the we are part of the medical team, like patients, families, you are a part of the medical team, and that record should absolutely be reflective of, like you said, your experiences and and what you remember about that encounter and not just the medical lingo and and all of the things that that the doctor recommended. Have there been surprises in your own chart? You know, have you read what your own visit summary and been, like, what?

Ilana Jacqueline: No. Absolutely. I mean because I really have read every single piece of of medical record that it has my name in it. Yeah. I mean, I've I think the one that always strikes me is, like, otherwise healthy young woman.
Is what is is used to refer to me as, and I'm like, I don't know anybody who has ever treated me or knows me in real life who would describe me as otherwise, I have a rare disease. I have a complex illness. I'm on immunoglobulin for the rest of my life. Like, I am very far from otherwise healthy young woman. And so I I mean and that one, I mean, obviously, that's not, like, derogatory in any sense, but, like, it just it kind of skews the narrative right out of the gate for me because I'm like you're not dealing with someone who's otherwise healthy.
You're dealing with someone who has an underlying immune deficiency and and that is treated differently than it should be. You know, there's you know, a history of sepsis and organ damage. And, you know, when I walk into an emergency room or a new doctor's office, like, I want precautions to be taken. And and I, you know, I I just wanna be described correctly. And, you know, and there are other things, again, not derogatory, but just funny that are, like, pleasant.
Patient is lovely, delightful, which is so flattering until you realize it's like a drop down menu of just, like, additives.

Dr. Nicole: I'm glad you brought that up, Ilana, you know, this idea of, like, descriptors in terms of, like, how you like how much you like a patient. Because some of the things that have been studied about stigmatizing language and medical records show that black patients in particular those kind words like lovely or agreeable or Yes. Delightful there's been studies that have shown that those words are much less likely to be used among black patients True. Latino patients. And they are much more likely to be described as, you know, difficult or whatever, didn't combative even.
Like, there's all kinds of words that land. And and again, these studies show, again, if and you all can imagine even if you're not in the medical field, if you're a doctor, you're reading a

chart, and it starts out this delightful otherwise healthy young woman versus a chart that starts out with saying that somebody's noncompliant Yes. Or, you know, they are combative or they're difficult or, you know, all of these things. It completely can shift how you approach that patient, how you approach their illness, how you approach how they describe, what's going on with them. Are there other groups of patients?
We know, like, race and ethnicity is a huge factor. You mentioned early like income, a lot of times lower income patients that are maybe on Medicaid versus private insurance. Are there other groups of patients in in your experience that are also more likely to have some of these disparaging terms and language in their chart?

Ilana Jacqueline: Absolutely. And I, you know, from the research, we know that black patients are the most documented, the most severe cases we have the highest maternal mortality rates. This is something that is, it's again extremely well documented. There are other populations that are starting to make their way into this research, and there's not there's not quite as much as we want to see yet in the research. I you know, as I was as I was going through the histories and the studies, for my book.
I I was hoping for more, and I think we're gonna see more over the next ten years, but definitely fat women, older women who are in a lower social economic class, women with psychiatric diagnosis of any kind, depression, anxiety, even the most minor mentions of panic attacks or anxiety or depression, postpartum depression. That that is a strike against them. In the file. Others who get hit hard. Again, patients in larger bodies, so they have their symptoms attributed to weight instead of investigated.
Patients on Medicaid, I think the situation with that is, like, they they don't even get the the thought to run more tests because they're not sure that they're gonna be covered. So they don't even suggest things or they don't even suggest medications that are, you know, something that could be a better first line treatment than something else. Patients with limited English, their ability to communicate definitely obstructs LGBTQ plus patients, disabled patients, older patients whose symptoms get filed away under aging. Everything is just aging. Young patients and minors who, again, like me, it was kind of like, well, maybe they have an ulterior motive.
They don't wanna go to school. They don't wanna partake in their responsibilities. And anyone with a pain a chronic pain history or a substance abuse history. That immediately gets a red flag for drug seeking behavior and and that's just that's it. That's the end.

Dr. Nicole: That's a nice that's a not nice. That's a long list.

Ilana Jacqueline: Yeah. It is.

Dr. Nicole: I mean, it's unfortunately, it's a long list. And to your point, many of those have not yet been fully studied. And I'm sure as we continue to do research in this area, more

categories are going to emerge. I would imagine that this is sounding a little bit scary to people who are listening who may fit in some of those categories that you just mentioned. And and while you and I are definitely going to talk about how we can advocate, how we can and should be advocating for ourselves.
I wanna take kind of a step up for a moment and look at the system because both of us, we recognize the portance of individual advocacy and also both of us do work with systems because ultimately it's the system that needs to be changed. It it always hurts me that we put so much burden on patients and families to, you know, arm them with things that they need to, like, help them navigate the system that shouldn't be so complicated and biased in the first place. So with your vast experience working in this intersection between patients and the healthcare industry, even including biopharma, what tools or policies or practices can be implemented that may help to curb the use of and the propagation of the stigmatizing language that we've been talking about.

Ilana Jacqueline: There are so many things going on with that. I barely know where to begin. I I almost wanna begin with one one thing for me that that feels exciting and relevant is that I I work a lot with AI, and and I'm doing a lot of research right now on how AI is, you know, integrating into health care in all the different ways. And I think the most hopeful thing that I know about that is that we are aware that that the the models that we had trained AI on are inaccurate when it comes to women's health when it comes to health across the board. And now we are retraining models of AI on more accurate information.
I think the scariest thing when patients look at, like, AI in the future is is the idea that the bias will that that AI will be trained on the bias. And and therefore, everything after all of our electronic medical records that use AI, all of our, you know, recording devices that use AI are gonna be inaccurate. But I think that just the the idea that we are still aware now that that everything that we've learned about medicine is lacking. Now we have space to fill in those gaps. And that's and that's what I've seen across the board that we're doing.
We're we're starting to do more research. But the other things, I think, are are kind of like workflow and and training. So there are a lot of medical schools now that are becoming more and more open to bringing in different groups, different patients who have complex illnesses, to tell their stories, to educate about medical gaslighting. I was so excited when I was researching for the book to meet people like Michelle Flum who is a professor at Xavier University who wrote the book on medical trauma and talking about how patients, you know, who experience things like, you know, a cancer diagnosis, a surgery waking up from anesthesia, you know, in the middle of a surgery being in the hospital during COVID and, you know, experiencing people, you know, in the next bed dying. I mean, so many things that happen in a hospital setting that truly traumatized patients that we kind of gloss over. You know, it's something that, you know, it's like, there's such a survivalism, a survivalism

attitude and healthcare that we're starting to change the tides of. We're starting to understand, like, you know, I understand this is normal, but it's not the best thing for us. And could we could we pay a little bit more attention to patients as a whole, you know, like holistically when they're experiencing emergency rooms, when they're experiencing long term hospitalizations, can we think also about their mental health? So I think I think that will have a huge impact. And then for for me, I really the thing that I try to educate patients and doctors on is just the model of participatory care.
And it's something that everyone wants. It's not something that anyone is against it. It's not a bipartisan issue. You know, it's just something that, like, everybody wants to be able to collaborate. They wanna have a real conversation together.
So, you know, there's a society for participant participatory medicine, and it's been around for about twenty years. And they're the creator of open notes dot org, which Mhmm. Were the heroes in getting us access to our medical records and and HIPAA and all of that. And they are still around and functioning and and coming up with new policies. So I think there's a lot of great advocacy being done right now that makes me again really hopeful that we're gonna see big changes over the next couple of years.

Dr. Nicole: Thank you so much for sharing that. And thank you for lifting up the Society of Participatory Medicine. I mean, they're they're groundbreaking groundbreaking work that that has continued and and so important in this space. And I love that you said, this is like this is kinda like a no brainer. It's not like Mhmm.
People are fighting about whether patients and families should participate in their care. It's that the systems in which we work. They just don't really support that. And so everybody's trying to have a work around. The patients are trying to work around a bad system.
The doctors are trying to work around a bad system. And, ultimately, we just need the system to be revamped. And I'm excited about some of the work that is happening. Really glad to hear that we are working on retraining AI because as you indicated, lots of bias, you know, built in to AI. And so that recognition and the the desire, the dedication to go back and rework that and fix that is incredibly important.
You mentioned that you've seen some things in your chart that were, you know, surprising Maybe after this podcast, people are gonna go back and look at some of those visit summaries and discover, like, wait a minute. I actually, it's so interesting just yesterday. We're recording this on a Monday. Just yesterday, I was in church and a church member was talking with me about a recent experience that he had where it wasn't necessarily stigmatizing language, but there was just incorrect information. There isn't there's information in his chart about a diagnosis that he actually doesn't have.
And medications that he doesn't take. And instead of doctors listening to him, he explained this this whole process where he was having to say, like, no, I don't have this. And they're

saying, well, it's in your record and it's in your last five notes. And so maybe you just forgot that you have that maybe you maybe maybe you're not taking it, but you forgot that you were supposed to be taking it. So if someone's listening and either they find inaccurate information or disparaging, stigmatizing language in their chart, what can they do? What is the recourse for a patient who sees that there's information in a record that should not be there?

Ilana Jacqueline: This is the number one question I get asked, and this is really I think it's really the reason that I wanted to write this book. And for me, I mean, just to tell you a little bit of of my personal story, this is beyond the immune deficiency disease. I was diagnosed in twenty twenty with intracranial hypertension, which is it's kind of like a headache disorder There's fluid on the brain and it's causes very, very, very painful migraines. And I I didn't know what was wrong with me. I was having all these very strange neurological symptoms and I kept getting denied an MRI.

And I kept going from neurologist Generologist being, like, please. I just I just need an MRI. And I couldn't figure out why it was that everyone was denying me or, like, not making it a a higher priority when I was having, I mean, very bizarre neurological symptoms. Like, I was having half my body go numb. I was having issues with language.

Like, I I was, like, forgetting words, which I I hope in listening to this, you would understand how strange that is for me. Yeah. I was having very severe memory issues. And I and I was not getting the help that I needed. And it really took me kind of digging into my file and realizing that I had been given some terminology in my medical record that was essentially saying I was like being a hypochondriac.

And I I had to eventually, at some point, it got so bad. My mother came to visit me. I live in Portland. My mother lives in Florida. She flew out to visit me.

I was really doing very badly. She could see that my face was completely swollen. That one of my eyes was, like, protruding. It was really bad. She she immediately was like, we're going to the emergency room.

Took me to the emergency room. We waited fifteen hours to be seen. And finally, I had an MRI. And as soon as I woke up, they were like, I had I had sedation for the MRI. But as soon as I woke up, they were like, we need to, like, drain we need to do a spinal tap to drain some of the fluid that's on your brain because my my eyes were being pushed forward I was having, you know, just my pitutary gland was being compressed. It was very bad. And that's the kind of thing that can happen when you have language like that. And I hadn't looked closely enough at my medical record at that time to realize that's why I was getting shuffled around from doctor to doctor and not getting seen was because there was this scarlet letter in my in my documentation that was saying, don't listen to her. It's not that important. And so and so I when I get messages from patients that are having the same situation

where they're they're getting these really ambiguous diagnoses that are basically saying you're crazy. Your hypochondriac, your hysterical, and and so many different words, and there's a lot of different phrases that they use now to say that that are not outright what they used to be. But the advice that I give them is is multi step. One is the advice that, you know, we kind of already talked about, which is, like, hey, you leave an appointment, you get that ping on your phone, you log in, and you read through that. That's your that's your update.

The other thing I'd really like to recommend is that you get your whole record. Now, what you see in my chart is not your whole record. It is just kind of like pieces of it. It's it's important pieces. You should read it, but it's not everything.

But you have the right to request your medical records and I have on my website, like, a PDF that walks you through the way to do it, like, going to the medical records, getting the medical records, phone number, fax number, or email, sending in your request. I give you exactly what to say in that request to make sure you're getting the entire medical record. And and then, you know, you they have thirty days to send that to you. It usually arrives in your my chart as a letter, and you can read through that. And that's something you wanna go over with, like, a fine tooth comb and make sure that you're not seeing any of those scarlet letters, those red flags, anything that would make a doctor say, okay.

Well, it's not that serious. It's not that important. So that's my that's my second advice is get the whole record. And then fix things immediately. So look at your medication, your dosages, your allergies, your height and weight, what pharmacy is on file for you.

We think that these are not timely and important things, but anything could happen to you at any time. You know, like, you could step on a rusty nail, go to the emergency room, and, oh, no, you didn't have in your file that you're allergic to specific antibiotics. And you can't talk or think or speak for yourself or advocate for yourself and suddenly now you also have, you know, like, Redman syndrome because you're so allergic to the antibiotic that they've given you. So always try and correct that when you are well, when you are well enough to go in there and advocate for yourself. So fix that inaccurate data that's in your file.

And then as far as, okay, a doctor's written something about me. It's not true. It's not factual. It's not based on what we discussed together. So that is a it is a legal document. They're they're the medical record. It's the doctor owns that legal document. So you can't go in and change that. And that's a very frustrating thing. I hate telling patients this, but I'm never gonna sugarcoat it.

I'm never gonna, like, you know, not give you the truth. It's not yours to edit. It's not yours. So you can request an amendment. You can write a message on my chart to your doctor. You can say, hey, I read this in the medical records. This is not what we discussed. This is not an accurate representation of what happens. Can you make an amendment? And you can always ask, will that doctor do that?

Not always. Not often. And then, you know, if that doesn't get corrected, kind of what I suggest is bury it, and this is a weird piece of advice. But if something is in your document, it's it's in your medical record, and it's sitting at the very top of it, you wanna go to a different doctor and get that corrected in their record, and then just try and move that down as far down as possible so that what doctors are seeing in the most recent notes are the more accurate notes. And again, it's it's not, is it the perfect workaround?
Absolutely not. Ideally, you and the doctor would agree, hey, that was a mistake and hey, that's impeding my care, but that's not always going to happen. So I want to be realistic with patients that you know, you may not have the ability to to delete that by yourself, but you can go to a different doctor and you should. I really do recommend for patients get a second opinion, get a third opinion, go out there and find someone who's gonna believe you because there are There are great doctors out there, and I'm so sorry that you had to go through some really bad ones to find the one that is gonna believe you and treat you, but please don't stop seeking care.

Dr. Nicole: Thank you along with that. This bury it. Like, I I you you caught me off guard with that one. I'm like, oh, that's good. That is not something that I had considered.
And and you're right. It does add a tax. To the patient to have to go to more and more and more doctors. But I love just that strategy about you know, because you're right. Most people are not gonna read through the whole thing.
So if the most recent notes are more positive, more accurate, that's good. And I just wanna reiterate what you said about never stopping and and just there are great doctors out here, you all. And, yes, sometimes, it can be hard. They can be hard to find, but you really do have to be persistent and not feel bad about firing. Your doctor, if they are not providing the care that you need and deserve, if they you know, if you're finding disparaging language, things that are not accurate, and you're not able to get them to reasonably make those corrections, to definitely do your due diligence to try to find someone else.
So thank you for that. So we talked to patients and families about what they could do. As we wrap up, carefully. Hopefully, there are some clinicians listening as well. What would you say to them about gaslighting, about the use of stigmatizing language, about bias? What What are some closing thoughts that you can share with clinicians?

Ilana Jacqueline: You are a patient before you're a doctor. At some point in your life, you're gonna be the one on the exam table and you're gonna want the the rules to apply to you and you're gonna want them to be their rules. And I in my advocacy, I never try to cast clinicians as the villains. I don't think that they are villains. I think that this is a extremely complicated, complex job and the responsibility is enormous.
And I really do see medical gas lighting as like a compounded result of speed, of exhaustion, of inherited bias, of a system that give you twelve minutes to diagnose a patient

with a rare disease. How are you supposed to do that? So I want you to just take into consideration that that one day you'll be in that seat as well, and you'll want the system to work just as well for you as you wanted to work for your patients. So things like continuing medical education, things like making room to understand, things like medical trauma and medical gaslighting. There's so much great there are great books out there.
I I am so thrilled not to be alone on the bookshelf. There are some fabulous books about medical trauma and medical gaslighting, the experiences of patients, anytime that you can bring in a case and present, hey, you know, we thought this was something psychiatric, or we thought that this was something else, and it turned out to be something that was easily solvable. Any clinicians speak with each other, they're always continuing their education. And and I I want doctors to to understand if a patient asks you to amend a note, you know, that's something that is a request to consider and to really hear them out before shutting them down if if possible.

Dr. Nicole: Thank you. Thank you so much, Ilana. Thank you for all of the work that you do in this space. Thank you for using your own personal lived experiences for good. And thank you for being a guest on bold conversations.
I have personally learned a lot. I'm sure that our listeners have learned a lot as well. I would love for you to share with the listeners how they can follow you, please share how they can get your books, anything else that you want to share as we wrap up.

Ilana Jacqueline: Thank you. And thank you so much for having me. Yes. So you can find me at ilana jacqueline dot com. That's I l a n a jacqueline dot com.
And I'm on social media, on Instagram, on TikTok, on YouTube at at ilana underscore jacqueline.

Dr. Nicole: Thank you so much, Ilana. And her two books are surviving and thriving with an invisible chronic illness, how to stay sane and live one step ahead of your symptoms, and then medical gaslighting, how to get the care you deserve, in a system that makes you fight for your life. And a lot I'm assuming, are these available on Amazon and in other bookstores?

Ilana Jacqueline: Yes. These are available on Amazon, on Audible, and at your local library.

Dr. Nicole: Thank you for saying that at your local library. Alright. Well, thanks again, Ilana, and thank you all for listening. It's been a little while. I'm excited to be back for bold conversation.
Stay tuned for another episode, and thank you again for tuning in.