John Moe: A quick note: this episode contains discussion of suicidality. I think this episode of the show might make you mad. It's *Depresh Mode*. I'm John Moe. I am glad you're here.

Transition: Spirited acoustic guitar.

John Moe: Look, I hope this episode—this interview—doesn't make you mad! I don't want anyone to be mad. It's just that the talk we're going to have today is kind of about challenging some established ways of thinking when it comes to mental health. If you think of yourself as having a certain mental health condition, if you <u>have</u> that identity, if that gives you clarity—well, the clarity might get a little fogged up today. That might make you defensive, but I encourage you to listen. You don't have to agree with everything, but listening anyway tends to be a good idea.

Today's talk is about challenging the reliability and usefulness of mental health diagnoses, challenging the idea of the <u>definitiveness</u> of a diagnosis—particularly the diagnosis as noun. This person <u>is</u> a depressive. That person <u>is</u> an addict.

Sarah Fay is an author, educator, mental health advocate, and a person who has struggled with mental health issues for most of her life. She's the author of *Pathological: The True Story of Six Misdiagnoses*, originally published in 2022 and rereleased this past summer. Sarah believes that mental illness is real. To suffer, to be in distress, that is real. To go to therapy for some help, that's useful and real. But the science—the cold, hard facts about the objective reality of it all? Maybe not so real. I talked to Sarah about mental health science and what she says were her six misdiagnoses.

Transition: Spirited acoustic guitar.

John Moe: Sarah Fay, welcome to Depresh Mode.

Sarah Fay: Thank you so much for having me. I'm very, very excited to be here.

John Moe: Good. Well, let's start with diagnosis one, which I understand happened at about age 12. What was that, and what had led up to it?

Sarah Fay: That was— My first diagnosis was anorexia, and that had been diagnosed by my primary care physician. So, my pediatrician. And the reason why that's important is because the five of the six diagnoses that I received were given to me by my primary care physicians. So, sometimes when we start to talk about mental health and psychiatry and that sort of thing, it can feel like a criticism of psychiatry. But in reality, it's more a criticism of the mental health system. Because we're putting all this onto pediatricians and primary care physicians when they're just not really trained to do this.

(John affirms.)

Anyway, I was in eighth grade, and I had not been eating. And so, at one point I could not hold down food or water. And so, they took me to the emergency room—"they", my parents—took me to the emergency room, rightfully so, and saw my pediatrician, and he said, "You're an anorexic."

So, again, it was that terminology. One, it was a word I'd never heard before. So, this was 1986. So, even though anorexia was definitely in the public conversation at that time, I was 12 years old. So, what did I know? And my parents knew <u>nothing</u> about it. So, what happened was that word came out, but not "you have anorexia," but "you <u>are</u> an anorexic." And that really stuck in my mind.

John Moe: It defines you.

Sarah Fay: Totally. So, it was already an identity pushed on me. But in reality, what had been happening was my parents were divorcing, and I was going to a new high school, and I was terrified, and I was really sad. And to this day, I always hold it in my stomach, and I can't eat. Like, I don't want to eat. So, it was pretty basic, but I was not doing the three key behaviors. I didn't exhibit the three key behaviors of an anorexic or someone with anorexia. And one was I wasn't weighing myself. I wasn't obsessed with my body image. And I was not counting calories and doing those sorts of things. So, if anyone had pressed a little bit, they may not have seen that—(correcting herself) or they may have seen that maybe this wasn't pathological, but a very normal response to the situation and what was happening.

John Moe: What happened as a result of the diagnosis?

Sarah Fay: At that time, they were not medicating people with anorexia. They do now, but that was a long time ago. So, now you might find that, you know, a young person is prescribed an antidepressant. I shouldn't call it an antidepressant, 'cause it's not really fighting depression, but an SSRI. *(Chuckles.)*

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And so, I didn't have that issue. Which is also important, because so many people get in the mental health system, and they're immediately given psychiatric medications. And once you're in that psychotropic drug... kind of spiral, in some ways you're being put on and taken off them very quickly. That didn't happen to me until I was in my 30s. So, this first part that of the time that I was in the mental health system, I was very lucky in some ways.

So, with anorexia, they took me to a psychologist. All I remember is he kind of was half in the dark, *(chuckling)* and it was a dark room, and it was very cold. And that's pretty much all I remember about him. So, you know, now I look back and I think, "Augh! You know, I teach at a university, and there are so many mental health services. And so, what if I'd gone to college? Or what if I'd gotten the right therapist?" Which isn't always easy. It probably isn't his fault. So much of therapy is about the connection. And so, basically what happened was I saw him, and then I continued to... I guess what a better way to say it is I became an anorexic.

John Moe: What do you mean?

Sarah Fay: So, it was basically—When the pediatrician gave me that diagnosis, I became—I started to identify as one. Right now, we have social media. And what people are talking about, there are pro-ana websites and pro-ana accounts. What that means is there are pro anorexia social media accounts where people counsel each other on how to be an anorexic. I did that (chuckling) in 1986 on my own. There was a book called The Best Little Girl in the World, and it was by Steven Levenkron, and he was actually Karen Carpenter's doctor. Doctor is the wrong word, 'cause it turned out that he did not have a medical degree even though her parents thought—her family thought he did, et cetera. But in this book, it's about a girl with anorexia. And it tells you— In some ways, it teaches you how to be one.

Now, I shouldn't say it as if nothing was wrong, because it did continue. There were things that were wrong. And then as we know, once you're in that spiral of depression—which had eventually taken hold; depression is an emotion; it's not necessarily a pathology. Once that happened, it was very hard to get out of it, and I couldn't. So, eventually I was in an outpatient program for eating disorders. And at one point, you know, I risked dying. And what they told my parents—or at least my mother—they said, "She will likely die of anorexia or suicide." So, that kind of prognosis was the kind of thing that was happening at that time.

Now, whether or not they would do that now for anorexia, I don't know. But I certainly got those kinds of dismal prognosis for other diagnoses that I received later on. And that's just to say that we don't talk about recovery as much as we should with mental health.

John Moe: Right, right. And I want to get to that and the idea of a chronic condition or not a chronic condition. But so— And we try—you know, I try in my own life as best I can to use the person-first language. Like, you know, my father wasn't an alcoholic, because that's— I mean, that's not all he was. But he was a person who had a problem with alcohol. He had an addiction to alcohol.

Did you feel that being called an anorexic set a course for you, that you would then fulfill this identity that had been given to you?

Sarah Fay: Absolutely. I mean, there's no question. Now, whether or not—

John Moe: Do you think you would've <u>not</u> done those behaviors if that had never been said to you? You would've just—you know—gone to the high school, adapted to it, and moved on?

Sarah Fay: (Chuckling.) Well, probably not. It was a very competitive high school. But no, it was a— I mean, if that hadn't existed, whether or not I would've stopped the behaviors, we don't know. But I certainly wouldn't have then read Steven Levenkron's novel and had this identity and seen myself— You know, there were other girls in my high school and in the kind of sister high school, so I could— You know, there were other girls doing this. I mean, that's very weird, right? So, again, if there was none of that, who knows what would've happened.

John Moe: So, you are called an anorexic. That's diagnosis one or misdiagnosis one. I mean, again— And I wanna move on to two.

(They laugh.)

And I know I have only so much time. But then do you assert, then, that you never had the condition known as anorexia?

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Sarah Fay: This is what trips people up so much about my book. And it's funny, because—First of all, never title a book a word like misdiagnoses, which is so hard to pronounce. People stumble all over it all the time. *(Chuckling.)* So, I did all this publicity for the book, and it was constant. I thought never—

John Moe: Yeah, yeah. You're stuck with that word, pronouncing that for the next several years. Yeah.

Sarah Fay: But what I talk about in the introduction, though maybe not—I don't reiterate it enough—is that basically it's not that nothing was wrong. Mental illness is very, very real. I suffered from serious mental illness for 25 years. There's no question. By the time I was in my 40s, I couldn't live independently. That's not faking it or even just an identity—you know, adopting an identity. That doesn't happen from there.

But what is true is that no psychiatric diagnosis can really articulate our mental and emotional pain. There's just no way. And I think any psychiatrist if they were on here would say, "Of course, we know that." So, there's nothing wrong with psychiatry, per se. I know some people are antipsychiatry. I'm absolutely not. They're not, in some ways, doing anything wrong. We're asking a lot of them. We're asking them—(chuckles). It's like, "Here. Here's my mental and emotional anguish. Solve it." You know? I mean, we're just asking them to do a lot!

John Moe: Sure, yeah. "Make me fine."

Sarah Fay: Yeah, exactly. The problem is that people don't know the truth about these diagnoses and that they are just labels. They're useful because we use them, but they're not scientifically valid or reliable. And I didn't know that. So, again, this idea that you adopt this identity—would I have done that if I'd known, "Oh, this is just like a little place marker that we're giving you to try to treat this"? That's the difference. So, how much are we over identifying and perhaps making our conditions worse?

When we think about it, mania, depression, anxiety, even psychosis have been around since ancient Greece. It's not like that's new or it's a contemporary thing. They're, in some ways, normal. Now, they do need treatment if they get to a point of dysfunction. No question.

John Moe: I want to get to the DSM-5 here in a little bit, because I know you have a lot to say on that. But just to give a sense of these series of diagnoses that you received, which one came after the eating disorder? The anorexia?

Sarah Fay: When I was in my 20s, I was diagnosed with generalized anxiety disorder and depression. So, major depressive disorder. One came from my GP, and actually one did come from, first, a psychologist. So, that one was actually from someone in the mental health system. But— So, yeah, those were the two I received. And with the generalized anxiety disorder, I was living in New York City at the time. I don't know if that has any relationship, but it was immediately like, "Here's valium." (*Chuckles*.)

That was it. No treatment. It was just my general—you know—practitioner who said that. My GP. And then, major depressive disorder—you know, that was something that the psychologist then wanted me to go see a psychiatrist. I did not want to. But with those—

John Moe: Why not?

Sarah Fay: Yeah, go ahead.

John Moe: Why didn't you wanna go to a psychiatrist?

Sarah Fay: Maybe I didn't wanna believe that it was true? You know, there's always that. Maybe I didn't wanna identify that. It seemed scary to me at that time. Also, I was living in New York, and I had no money. (*Laughs.*) I had no health insurance. So, that'll pretty much do it. But again, thinking about my life at that time, I was living in New York. I lived in a bad neighborhood. You know, I had— I was economically insecure. I had a lot of things that could contribute that we don't talk enough about, especially financial security, that could lead to depression and certainly anxiety.

John Moe: You know, from there— I know you eventually were diagnosed with bipolar disorder. Type two, I believe? Is that right?

Sarah Fay: So, then it was obsessive compulsive disorder.

John Moe: Obsessive compulsive. Okay.

Sarah Fay: Then ADHD, attention deficit hyperactivity disorder. Then ADHD and OCD with anxious and depressive features. That was my favorite. It was like a salad. *(Chuckles.)*

John Moe: Wow. Yeah.

Sarah Fay: It was like a full salad of diagnoses.

John Moe: That's a combo platter right there.

Sarah Fay: Then bipolar two, and eventually bipolar one.

John Moe: I mean, how did that feel when A turned to B, and B turned to—I guess—F eventually? Did it feel like the truth over and over? And did you gravitate toward that identity the way you did when you were 12 with anorexia?

Sarah Fay: Absolutely. Every single time. Less so in my 20s.

John Moe: You felt like it had been cracked. Like, "Okay, now I've—this is what I actually—"

Sarah Fay: Yeah. So, I read all the books. And I think the other thing going back to me not being on medication early on is that I tried everything.

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I tried to meditate it down. I mean, I went to Thuong Hanh Monastery. I mean, I tried to meditate it down. I tried to yoga it away. I lied on the floor with mindfulness. I washed dishes and felt the suds. I mean, I did it all. (Chuckles.) And nothing worked. I ate immaculately. I didn't drink; I'd quit drinking. I didn't do drugs. So, all these—I didn't smoke. I mean, all these things that can really contribute to mental illness. And that's not a—you know, that's not a moralized thing. I'm not condemning any of those things. But they do play a role. I had none of that. So, I really did everything I could, I felt, before I took medication in my 30s.

John Moe: And how did it eventually stop at six?

Transition: Spirited acoustic guitar.

John Moe: We'll get the answer to that and what a post-diagnosis life looks like after the break.

Transition: Gentle acoustic guitar.

John Moe: Back with Sarah Fay, author of *Pathological: The True Story of Six Misdiagnoses*. Just before the break I asked her what happened after diagnosis—or misdiagnosis—number six.

Sarah Fay: So, what happened was—I mean, I was—You're right that I was always thinking, "Now we've found it." And then, when I was given the bipolar two diagnosis—which quickly went to bipolar one—by that point I had been in and out of partial hospitalization programs. I had been off and on medications—you know, antipsychotics, antidep—SSRIs, lithium, everything. And so, it was—And I could no longer live independently. So, that was a big, big turning point. Now, a lot of people say, "You were so successful."

And I mean, yes, I have a PhD; I have an MFA; I did write for *The New York Times*, but people have to understand, actually, that was easy in comparison to working at McDonald's. And people don't understand that, because academia is very forgiving. *(Chuckles.)* And I taught, you know, three days a week. If I had to go to a job 8AM to 4PM or 5PM—or whatever it is—or 9PM, I would've been fired after the second week. So, again, I found my way into something, and I was very lucky. But even then, I still was not living independently when I was in my 40s. So, I had a psychiatrist who was also my therapist. Terrible idea.

(Chuckles.) Ill-advised. Just 'cause you have no one to talk to about your therapist and no one to talk to about your psychiatrist.

So, I ended up— He and I had kind of a falling out and a parting of the ways. And I said, "I wanna still see you as a psychiatrist, but not as a therapist."

And he said, "No. That's not—I won't do it." And he wouldn't refill my medications.

So, I was coming up on them. I was suicidal at the time. And my sister— You know, again, we don't— The families have at the hardest, there's no question. My sister just swept in and found me a psychiatrist, and it's the same psychiatrist I have today. And yes, I do still have a psychiatrist. And I went to him, and he and I were sitting there. It was our intake. So, you're— You know, it's 27 minutes or 30 minutes or whatever. And I waited at the end of it for him to either reify the bipolar one diagnosis or give me a new one. (Chuckles.) Diagnosis number seven.

And instead, he looked at me and he said, "I don't know what you have."

And it just like blew my mind open. No one had <u>ever</u> said that. We're talking about primary care physicians I'd never met in a 15-minute office visit telling me I have ADHD. So, no one had <u>ever</u> had either the humility or the wisdom to say, "I don't know yet." And so, that just really opened everything up for me. It was life changing. And I remember leaving the office, and it was a really cold Chicago day, and just everything looked different. It looked harsher. You know, the trees looked harsher, and the sidewalk was all cracked. And you know. And in Chicago it gets this kind of like white, salty, terrible cold look to it. So, it looked harsher, but it also looked clearer—like, the sky was clearer.

And so, I ended up— From that moment on, I just decided, "What are these diagnoses I've been given?" And because I do have a PhD, my happy place is research. So, I just started researching the DSM and psychiatry and the history of psychiatry. I read everything I could. And that's when I learned what diagnoses really are, and it changed everything.

John Moe: Yeah. That's a huge breakthrough.

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When you talked about being so ill that you were suicidal, you were unable to live on your own and take care of yourself, do you think that was a result of taking meds that you shouldn't have been taking? Because these diagnoses were inaccurate?

Sarah Fay: I mean, certainly my family would probably say yes, and other people would probably say yes. I just don't know what led to that. I just don't know how it got so... so bad. I mean, I'm very lucky in so many ways. I have support, and I have a lot of resources. I still had a— I was still working. I was still adjuncting, you know, part-time. And so, I mean, I think it's a pretty good— There's a high likelihood that the medications had something to do with it. I'm loathe to say that, only because I think medications have been very helpful for

me. And we tend to demonize them, and I don't think that's appropriate for a lot of people. So— And a lot of people misunderstand recovery because of that too.

Like, "Oh, wait. I have to get off my meds, and I can't see a therapist, and I can't do this. And I'm free and happy and running through fields all the time." (*Laughs.*) Like, no, that's not recovery from mental illness. And so, it could have ended up like that. I mean, there's no question at that time I was being taken off and put on different medications so rapidly that there's no way that was a good idea. And I have a very sensitive system, so it's possible.

John Moe: So, then after the doctor said, "I don't know what's wrong with you," were you off all meds at that point?

Sarah Fay: No, I was on five different medications.

John Moe: Oh, but then after he told you that, did you stay on those meds?

Sarah Fay: Yes. And I recommend anybody listening to this call: do not do it alone. I have tried that in other situations. It is a terrible, dangerous idea. Withdrawal is harrowing and not something to take lightly from any medication. And so—But once he said that, what was interesting is I trusted him. Really, the best way to earn someone's trust is say, "I don't know."

(They chuckle.)

It's so freeing in your life too. I'm saying outside of a psychiatrist. Say you don't know. Say you don't remember. That's the human experience.

And so, when he did, then I wanted to see him more. And so, I went back, and he said, "We've gotta clean up this mess of meds"—that's a quote—"that you're on." So, he slowly kind of filtered out what was working and what wasn't and what was useful and what wasn't. So, then I went down, and eventually I was on three, and then eventually went to two. And that took a very long time, because titrating down and weaning off medications is serious business. And most people come off way too fast. And also, most people think you have to come off completely. And that's not always true for people like me, where I've been on it—I was on it for 15 years. That's a long time. And my body was completely dependent on them.

So, anyway, we— You know, we continued; I continued to see him, and he asked me one day— You know, he had a diagnosis for me, because he has to. And he said, "Do you wanna know your diagnosis?"

And I said, "No."

I still don't know what he wrote down to this day. And I'll never ask. Because I would become it. I would believe it. And it was just what I had been conditioned to do. And I just was done with that.

John Moe: So, you start looking into psychiatry, you start looking into the DSM-5—the latest edition of the Diagnostic and Statistical Manual. And what did you come up with? Like, what did you come to believe from that investigation? Because that's—You know, even on this show, we reference the DSM-5 all the time.

Sarah Fay: Yeah. I mean, I believed that diagnoses— I believed this sort of cliche that psychiatric diagnoses are just like physical diagnoses. That depression is just like diabetes. Which actually, we know a lot more about diabetes now, and maybe that's a little more true. But "it's like heart disease," and it's just not true. You cannot— What I learned is that— And I had pictured men in white coats and lots of microscopes and petri dishes and that sort of thing, *(chuckles)* discovering all these diagnoses. There are 541 diagnoses in the DSM-5, depending on how you count them. And we started with 152 in the DS-1. So, it seemed to me that there were just these discoveries.

But in reality it was just— The DSM-1 in 1952 was just, you know, eight men or so sitting around a table thinking up these diagnoses. That was it. And I shouldn't say they were thinking them up. They had been using them in some ways as—you know, to communicate. And the DSM was meant to be just for doctors to communicate with each other. Even up until the 1970s, people never knew their diagnoses. You just got treated, and it was just for people.

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But with the DSM-3 and Robert Spitzer, he made it popular. So, they not only expanded a lot of the criteria and introduced new diagnoses, the DSM became a bestseller. Like, what is that?! (Chuckling.) Like, it should not— It's a medical manual, but it got into the hands of people outside of psychiatry and people who would really be using it and eventually into the general public. And now look at us. We're diagnosing ourselves, and we're diagnosing each other. They're a part of our vernacular. But what I really did learn was just that they are not scientifically valid. And what that means is no one could prove, outside of my reported symptoms and a psychiatrist's opinion or a doctor's opinion, that I have any of these diagnoses or disorders that they were telling me.

And that was nothing I had ever suspected. I just thought there was more to it. And it's not. It's completely subjective. And then that they're not reliable—that I could sit in front of two different psychiatrists, and we could have the same interview or intake, and they could diagnose me and would most likely give me two different diagnoses. So, they're not reliable from physician to physician or psychiatrist to psychiatrist. So, why was I getting OCD and then ADHD? And possibly I could have seen the same—you know, two different doctors at the same time and received those two different diagnoses.

John Moe: So then, is that the fault of the DSM—or the authors of the DSM—for saying "this is how to use it; you know, identify one of these, and that's the team that you're on," or is that the fault of people for misunderstanding this quest for pretty abstract definitions to clusters of human behavior?

Sarah Fay: I mean, I wish I could say that it's just us, that it's just people. But it's not. And Robert Spitzer especially really promoted this sort of Chinese menu checklist of symptoms.

John Moe: Who's Robert Spitzer? Can you tell us about him?

Sarah Fay: Robert Spitzer was really the architect of the DSM. He chained— He was the one behind the DSM-3 who popularized it, who made it a bestseller, but also created these checklists of symptoms. So, when I'm diagnosed with major depressive disorder—if we were to open the DSM right now, you would see this list of symptoms. And there are nine of them, and I have to get five. *(Chuckling.)* Like it's a like it's a contest or something. Like it's a test. I get five, and then I have major depressive disorder. So, you know, that is how psychiatry works now. And he invented that.

What's interesting is when Spitzer was interviewed, they said, "How did you come to decide five of nine symptoms meant that a person had major depressive disorder?" And this was asked because there are over 1,000 different combinations. In reality, no one's depression diagnosis is like any other. You know? There's so many combinations of those symptoms. Or very few are like that. But he was asked, "How did you come to five out of nine?"

And he said, "We just went around the table. Four seemed like too few, and six seemed like too many."

Like, that is a quote from Robert Spitzer! (Chuckles.) And this is the same diagnostic tool we're using today. So, that was—You know, Spitzer—You asked if it was psychiatry's—I don't wanna say fault, but you know, "Is it the responsibility of psychiatry or people?" So, up until—you know—Spitzer really promoted it and really created this structure that made diagnoses the point instead of treatment the point. Allen Frances was the—He was one of the heads of the DSM-4, and he also was instrumental in the DSM-3 and knew Spitzer very well. And we'll get to the DSM-5. But Allen Frances was responsible, for instance, for expanding the criteria of autism and expanding the criteria of bipolar two.

And he has since come out—and I respect him so much, because he wrote an amazing book where he basically said like, "I made a mistake. This was—this is my fault. And this epidemic of autism and this epidemic of bipolar disorder is because we expanded the criteria. It has nothing to do with anything else. We changed how it could be diagnosed, and that's what did it."

Now some people would say, "Oh, that brought awareness, et cetera." Not really. I mean, if you say that someone has a fever if they're at 96 or above, you're gonna have more people with a fever. (Chuckles.) Like, that's just how it is. So—But I really have respect for him and other people who've really come out and admitted where they made mistakes.

Another person is Tom Insel, and he was head of the NIMH—the National Institute of Mental Health—for 13 years.

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And he really was the one—So, in tandem with the DSM-3 and 4 came this push toward the biomedical model that said, "Everything is biological." Right? So, I have a—

John & Sarah: (In unison.) —chemical imbalance—

Sarah Fay: —which is not a thing. And so—

John Moe: (Interrupting.) Wait, what do you mean chemical imbalances aren't a thing?

Sarah Fay: Oh, well, it's been disproven, and it was disproven a long time ago. And it was a pretty shaky theory anyway, but this idea that there is— I mean, basically what an SSRI does, we don't even know. So, calling it even an antidepressant was something that the pharmaceutical companies did. They labeled it as an antidepressant, but it doesn't target depression in any way. It's really throwing spaghetti against the wall. And you know, if it helps someone, great. And I've had great success with some of them, and other people have as well, but it's not as if it's a targeted treatment. Because it's not a chemical imbalance that then this drug goes in and fixes. So, those, chemical levels of serotonin—for instance—can be very high in some people with major depressive disorder and very low in others. There's no consistency, really.

So, anyway, Tom was head of the NIMH. And as he said—I think he said, "I spent \$20,000,000,000 on some really cool studies." So, when you think of those very pretty pictures of people's brains, and this is where it lights up for schizophrenia, and this is where it lights up for major depressive disorder. All of those studies he funded in the NIMH. And the goal was to prove that the DSM diagnoses are biologic—caused by biology almost solely. So, meaning, "It's in me, there's nothing I can do, and I'll have it forever." Right?

So, it's this maintenance model, meaning the best I can do is manage my symptoms. And so—But Tom has, as of a few—maybe it was five years ago—came out and said, "Mea culpa. I made a mistake." And he tells this really great story about giving a talk. And he had been showing slides of brain studies for people with schizophrenia and what they've seen and talking about all kinds of, you know, studies that they've been doing and the biology of this or the biology of that. And a man stood up during the Q&A and said, "You're telling me about the composition—the chemical composition—of paint, and my house is burning down. Like, my son is living on the street and doesn't even know who we are. Like, what are you doing?" (Chuckles.)

And he said it just changed him completely. Like, why are we wasting all this money on these studies that are never going to find one cause for any of these? It's not possible, because they were made up. They're in a book. Like, they're not real.

John Moe: So, do you assert that there is no such thing as mental illnesses? There's just a response to the life that we're living and the stimulus that we're receiving and the trauma that—if trauma is even a thing—that we've undergone before?

Sarah Fay: Then we wouldn't have had psychosis and mania and anxiety and depression in ancient Greece when we still wore togas. *(Chuckles.)* Like, whatever, when we still got to wear sandals all the time.

So, that's just absolutely not the case. You know, any study into the literature or the kind of the literature of psychiatry—which Edward Shorter does a beautiful study of—it shows that those things have always been with us. It's real. Mental illness is very, very real. I suffered from it. It's just that the terms that we're using—the diagnoses that we're using as facts do not actually describe those conditions in the way that we think they do. They aren't a thumbprint; they're just a label. And if people—if I had known that—

So, my ideal scenario would've been, "Sarah, we know that you're really suffering." I mean, I was chronically suicidal. So, "We know that you are really, really suffering. And what we're gonna do is I'm gonna use this diagnosis. We don't know a lot about the brain." Which is true, and everybody should start admitting to. "And these diagnoses are really just placeholders. But they're useful, 'cause it will help me get you this medication. So, this is the one I'm gonna use. This is the medication I suggest. This is why I suggest it. What do you think?" And then we could have had a conversation. Now, I know that when I was in crisis, that wouldn't have been possible. So, I know that's a really idealistic. And there are situations where the "let's talk about it" could never have happened.

But just knowing, "Oh, wait, I don't have to worry about this. I shouldn't spend all my time thinking about this diagnosis and instead think about getting better," which no one offered me the alternative or the option to get better ever. No one ever mentioned recovery to me until the very end.

[00:35:00]

John Moe: Yeah. I mean—So, is this—And I know that you're an author, obviously. You're a writing instructor. You have a lot of thoughts about commas and colons in this book. *(Chuckles.)* Do you think this comes down to a language thing?

(Sarah confirms.)

If I say, "Okay, you know, I can either say I am a depressive, I'm a person with major depressive disorder, I have been diagnosed with major depressive disorder, or I have a series of behaviors and thought patterns that have been coded as major depressive disorder in order for me to get insurance coverage."

Like, does it come down to "I am" versus "I have"?

Sarah Fay: Yeah. I mean, you know, that's very much simplifying it. But when we look at social media and especially young people where it is so much an identity— And again, that doesn't mean they're not suffering. That doesn't mean something isn't wrong necessarily, but it also means that there is social contagion. That's a real thing. And I know that that will upset some people, but I don't think that there's a risk in saying that. Because it's just a reality with anything. What we wanna do— We basically put the diagnoses into the wrong hands, which is us. They were never meant to be used by us. And this is giving psychiatry—kind of cutting them a little slack. Because it was only meant for doctors to communicate with each other. We were never meant to have these. So—

John Moe: Well, what's so bad about being transparent about what's going on in your life? Of giving the patient all the information I can get? When I have like a blood test done or an MRI done, I get a looong, detailed report. I can't make sense of a lot of it. But I get, you know, as much information as I possibly can. What's the damage there?

Sarah Fay: There's no MRI. There's no blood test. These are just theories. This is just impressions. These are just subjective ideas, and that's the reality. Now, again, there's nothing wrong with it <u>if</u> we were honest about it. And I should say, when the book came out, we were really preparing for pushback from psychiatry and the mental health community. And especially because an additional revision of the DSM-5 came out the same month my book came out, so we were just <u>ready</u> for it. And none. Like, <u>none</u>.

I spoke to the most wonderful psychiatrists and mental health professionals, and all of them looked at me and said, "We know. We know it's inadequate. And this is what we have." And I agree. I don't have a replacement, so I can't— I don't think we should throw the DSM out the window. I don't have like an alternative. If I did, I would say, "Let's do it." But I don't. And so, that was really surprising to me. I mean, I was even on NPR with Paul Applebaum, who's the head of the DSM-5 steering committee. And he basically said to me, "You're right. The public deserves to know." And that was an amazing moment for me. But where we got a lot of pushback was from the public. People did not wanna hear that their diagnoses are not scientifically valid or are unreliable.

Transition: Spirited acoustic guitar.

John Moe: I don't know what your experience is with this interview. I find a lot of stuff that makes sense. But there are also moments where Sarah talks about psychiatric diagnoses being not scientifically valid. And I kind of tweak a little bit when she says that, because it feels like she's saying my suffering isn't real, that my depression isn't valid. Upon reflection, I don't believe that's what she means. Indeed, there's a lot of research saying that because these conditions aren't provable in a scientific study, they are technically not scientifically valid. I find a lot of research also that says while that may be the case, they are useful, because we can look at treatments that have worked for other people in these situations.

It's also true that the chemical imbalance theory of depression has been found to not hold water, really. A bunch of research came out about that three or four years ago. The cold, hard scientific method reality of it doesn't back the theory up. More with Sarah Fay after the break.

Transition: Spirited acoustic guitar.

Promo:

Music: Playful, jaunty backing music.

J. Keith van Straaten: Hey, I am J. Keith van Stratton from *Go Fact Yourself*, and I'm here with MaxFun member of the month, Josh Mentor—who has been a Maximum Fun member since 2016! Hello. Josh!

Josh: Hey, J. Keith, how are you doing today?

J. Keith: I'm so well! And thank you so much for being a listener and supporter of our show. What made you decide to support MaxFun in general and to support our show, *Go Fact Yourself*?

Josh: Jordan Morris on *Jordan, Jesse, Go!* has a thing that he likes to say, which is, "You know, you tip your bartender a buck a beer; you tip your podcaster a buck a month." You know, I get way more use outta MaxFun podcasts than I do like Disney+ or Netflix.

[00:40:00]

J. Keith: Well, it's something we very much appreciate. And by the way, when was the last time Netflix selected you as a member of the month?

Josh: Eeeexactly!

J. Keith: Exactly! Josh Mentor, congratulations, and thank you again for being the MaxFun member of the month!

Josh: Thanks so much, guys.

Speaker: Become a MaxFun member now at MaximumFun.org/join.

(Music ends.)

Promo:

Music: Fun, exciting music.

Allan McLeod: *Walkin' About* is the podcast about walking. It's a walkumentary series where I, Allan McLeod, and a fun, friendly guest go for a walkabout. You'll learn about interesting people and places and have the kind of conversations you can only have on foot! We've got guests like Lauren Lapkus.

Lauren Lapkus: I figured something out about this map, like how to read it.

Allan: Betsy Sodaro.

Betsey Sodaro: I had no clue. That's awesome and nuts.

Allan: Jon Gabrus.

Jon Gabrus: This is like a great first date for like broke 20-somethings, you know?

Allan: And more! Check out Walkin' About with Allan McLeod on Maximum Fun.

(Music ends.)

Transition: Gentle acoustic guitar.

John Moe: Back talking with Sarah Fay, author of *Pathological: The True Story of Six Misdiagnoses*. She's been talking about how mental health diagnoses are not scientifically valid. She says the biggest pushback she's received on the book has not been from scientists but from the public, who hasn't liked that "not scientifically valid" thing.

Sarah Fay: We have become already so attached to them, and we see them as ourselves, that that was really not what people wanted to hear. Now, that's changing. So, I rereleased *Pathological* this summer, this past summer. So, it came out in 2022. So, we were midpandemic. It was not a good time, and everybody was not feeling great—rightfully so. So, it was not great timing in terms of that. But now, when it came out in July, the reception has been totally different. Now, it got great reviews and everything, and it sold really well. But the like the kind of rhetoric at that time was "everybody go get a diagnosis; get your child a diagnosis; this is the thing that's gonna help."

And now, people are thinking, "No, look at my child." Like, they're talking on Instagram and diagnosing themselves, and no psy— You know, people are walking into therapist's office and telling the therapist what they have, telling the psychiatrist what they have.

John Moe: Do you think that a GP or a psychiatrist should not tell a patient a termed diagnosis?

Sarah Fay: Well, obviously I thought it was right for me, because that's what I've done. But I mean, you know, at this point— I mean, that would get into a lot of sticky situations, and especially with forced medication and forced hospitalizations. I mean, this is just getting—it would get— I can't say that, obviously. But I do think that— You know, one thing that Allen Frances said, which <u>no one</u> said to me was, "Get a second opinion."

Now, I know that takes—that's also a luxury. Not everybody can do that. But wow!

John Moe: It's hard enough getting a first opinion on it. (Laughs.)

Sarah Fay: Exactly! But even just that is a very different way of thinking. And we do think about—you know, when we go in other respects in the medical profession, like we see other people in the medical profession, we do think that way. We don't think they're infallible and that they know exactly what's wrong. We'll think, "Well, maybe I should ask somebody else." And certainly, insurance could cover things like that. I mean, there's also—a lot of this is an issue with insurance too. And just those sorts of things I think can be really—can change the way that we receive diagnoses and the way we think about them.

John Moe: Do you think there is a... (sighs and "oof"s) an evil—

(They laugh.)

—plot from big pharma to encourage this self-diagnosis, peer-to-peer diagnosis, identifying with a diagnosis in order to sell us more pills?

Sarah Fay: I mean, it's so— It's very hard to read the history of psychiatry and pharmaceutical companies and psychiatric medications and not think that. (*Laughs.*) There was a lot of good evidence. But again, I think— I mean, one of them is—generalized anxiety was diagnosed in 1% of the population. This was—so, I wanna say 30 years ago. And what happened was Eli Lilly had a new drug coming out, and they wanted to attach it to a certain diagnosis. They dug around and the DSM, came up with this unknown diagnosis called generalized anxiety disorder, attached the medication to that disorder. And boom. What is it?

[00:45:00]

It's 40% of people are diagnosed with generalized anxiety disorder today. So, again, of course we're gonna think that. I mean, I don't— And certainly people like Robert Whitaker, of *Mad in America* have made a very good case for that. There's no question. And others.

John Moe: Now, a lot of people—I think—take comfort in a diagnosis. They feel like there's an explanation for this problem they've been having; there's a term for it, and therefore a community of other people, of teammates—like I've said—who are going through this scary thing at all, and that there's a protocol for at least how to attempt to address it. Do you think that's dangerous for them to think that, if they take comfort in it?

Sarah Fay: Not at all. <u>If</u>—and this is a big if. So, the first if is, okay, these are not scientifically valid or reliable. Alright? I take that with a grain of salt. It feels right to me, this diagnosis. It feels like, okay, this is answering a lot of questions for me, or it feels accurate, whatever that is. Great. You wanna accept your diagnosis, go for it. That's like not my— You know, my goal is not to have people not accept their diagnoses. But the other problem with that is then let's talk about recovery, and let's talk about it a lot more than we are. Because we don't talk about it at all.

And so, when we think about physical illnesses that have that kind of community—let's just talk about breast cancer. Imagine if they just said to <u>every</u> person with breast cancer, "You'll never recover." Even if we knew you could. Like, we're just not gonna talk about it. That is what's wrong. So, again, that community, absolutely. But what happens is that community

becomes focused on this old idea of the biomedical model and the maintenance model that says this is biological; you can never recover from it; the best you can do is manage your symptoms.

So, there are two types of recovery. There's clinical recovery and personal recovery. So, for a long time—or in physical illnesses—we are asking for clinical recovery. You take a test, and it says you are—you know, you're in remission, and we know. Right? There's these tests. But our diagnoses don't have those tests. So, how do we know? And with that, with clinical recovery, they still had that in psychiatry. But it would mean that the psychiatrist would say, "Yes, you're better, you're functioning," whatever they would decide. Because remember, they leveled the diagnosis. And so, now they can— You know, they're the ones who have to say if we're recovered or not. And what personal recovery is, is that we set the standards for our life. 'Cause we're getting into a lot of murky areas here, like you said. So, what makes me recovered? Do I have to be happy all the time? Do I have to—?

I mean, I'll tell you the story of how recovery came into my life, 'cause I think it speaks to this a lot. So, the same psychiatrist that I had, I had <u>never</u> heard that recovery was possible. And in one of our sessions, he was talking about a patient of his—obviously not by name—who was diagnosed with schizoaffective disorder. Longer story, but eventually she recovered and became an executive at Google.

And I was like, "First of all, you do not recover from mental illness. And second of all, you don't become an executive at Google." But that was when I started to research recovery and found all these communities of people who <u>had</u> recovered and that recovery <u>is</u> possible. but my idea of recovery was like, "Oh, you become a Google executive."

(They chuckle.)

You know, because I used to call it Google Executive Well. And obviously, I do not see that as recovery. (*Laughs.*) So, don't worry, but—

John Moe: So, how are you defining recovery here?

Sarah Fay: Yeah, no, exactly. So, the way Larry Davidson talks about it, which I think is useful, is that each person defines it for themselves. And that's in conjunction with your physician at the time or your mental health professional at the time. And you come up with what is going to be a functioning life for you. I mean, if you're functioning, you're functioning. Now, I know that gets into a lot of kind of ideas about capitalism. So, "can you work?" or you don't, and et cetera. But let's just say that you are not chronically suicidal. Like, that's a pretty clear, good line right there. (*Laughs.*)

(John agrees.)

There are certain lines that we can draw in each person's life of what would be recovered to me, and what that would look like. And it doesn't necessarily— I mean, it obviously doesn't mean becoming, you know, an executive anywhere. But it is— You know, I know what functioning is. Now, my life of recovery does not look the way people think it will. I have

panic attacks. I've been having them terribly for the last two days. My mother died a year ago, and it's coming up on the anniversary of her death. Of course. No one tells you that panic is part of grief. (*Chuckling*.) They should have told me that.

John Moe: Yeah, they should have.

Sarah Fay: I've gone through grief, you know, over the last year, like I've never experienced before.

[00:50:00]

And you know, I do have low days, et cetera. I <u>really</u> don't like to go out. (Chuckles.) I live a lot in my house. I'm very happy with my two cats. I don't want a romantic relationship. I never did. It was—it's just not right for me. So, part of it has been very empowering, which is like, "What do I want my life to look like? What is <u>actually</u> gonna make me happy?" And it's not what people think. And it's been really exciting to see what that actually looks like for me. And of course, it's changing. You know, as my life changes, I welcome new things and all of that. But I really like being—I mean, someone would say that I have social anxiety disorder. (Laughs.) And I do not!

John Moe: Yeah. Well, I mean, disorder— Like, this is one of the first lessons I learned in— I'm not a psychologist or psychiatrist; I'm a talk show host. But one of the first things I learned was like, okay, so you're telling me that whether something is a disorder or not—like, whether it's the mood of depression or the major depressive disorder depends on the functionality. Like, can I get outta bed? Can I make breakfast and dinner for my kids? You know? Like, can I—? No? It's keeping me from doing that? That's a disorder. I can still do that, even though I have this feeling? Well, then it's a feeling. You know, and it is a sort of inexact thing. So, I think for a lot of people, the idea of recovery represents—you know, even that term represents "the bone has knit together," if we may return to the other analogy. "The bone has knit together. I don't feel it anymore. It's like it never happened."

Sarah Fay: But let me just— I'm just gonna—just 'cause the metaphor is so good—is that when bones actually heal, some heal perfectly, and some heal not perfectly. *(Chuckles.)*

John Moe: A little wonky. Yeah. Yeah.

Sarah Fay: So, like some people can break their ankle, and walk forever with a limp. And some people can run a marathon a year later. Like—So, again, I think it is gonna be person to person. So—But you're right in that, if Larry Davidson was here, he would say, "Yeah, we don't like the word recovery." One, it's conflated with addiction. And then, you know, there are different mechanisms there, et cetera. So, yeah. I mean, definitely "recovery," we don't have a great word for it. That's for sure.

John Moe: But, what it sounds like when you talk about recovery and believing that recovery is possible, you are talking about functionality. You're talking about, "Yes, I can go on. Yes, I can have a fulfilling life." But it's not—it may be for some, but not necessarily for everybody—feeling like it never happened in the first place.

Sarah Fay: Oh yeah. No, I mean, it's 25 years of my life, I can't possibly not—(laughs). You know, it dictated all of my life for 25 years.

John Moe: You wouldn't call yourself cured, but you'd call yourself in recovery. Is that fair?

Sarah Fay: Well, I use—So, I wrote the sequel to *Pathological*, which is called *Cured*, and I used that term very deliberately. And it is—I serialized it on Substack. And you know, the way that I use it is the verb. So, "a cure" means like silver bullet, right? <u>To</u> cure is actually self-care. So, I see it as—not like I could slip at any moment or anything like that, but there were—of course, there are conditions. I mean, if I started drinking and doing drugs tomorrow, I don't doubt that I would be on a very fast road to having—

John Moe: A bad part of town.

Sarah Fay: Yeah, exactly. So, again, just thinking of that, it is a process always—and for all of us all the time. Because things can happen. Like, you know, you can lose a parent or a child or something like that, and it doesn't mean it's pathological. What I was thinking about is, for the pathologization of grief, it is— I think more than one year of grieving is considered pathological. And you have—you know?

John Moe: Right. Prolonged grief disorder. Which is ridiculous.

Sarah Fay: Disorder. Exactly. And I was thinking about that disorder. I was thinking about that this morning, and I thought, "You gotta be kidding me." Like, I'm just on a year and I feel like a baby in grief, you know? I just—yeah, it's wild. That's the kind of thing though. So, if psychiatry— If the DS M didn't pathologize, you know, very traditional, everyday experiences—everyday life, as Allen Frances said—it wouldn't really be as much of a problem as it is.

John Moe: Would you recommend—I mean, would your argument indicate that what we should do is look for *(sighs)* information about the things that we're experiencing? The pain in our hearts, the challenges that we're facing, the physical/mental/emotional symptoms that we're carrying—

[00:55:00]

—get enlightened through our research, through talking with qualified trained experts, and carry that with us, but don't join a team? Don't define ourselves by a diagnosis?

Sarah Fay: Well, I mean, I think it's great to join a team if that makes you—you know, if that helps, like no question. But I think—

John Moe: Alcoholics Anonymous, for instance.

Sarah Fay: Yeah, whatever it might be. I mean, I think that— First of all, having been through so much severe mental illness, it's not logical. And we're really not in a position to do

those things. I was on my way out of something, and I had very good care by the time that happened. In the midst of my chronic suicidality, I never could have done this. I never could have. I was completely at a loss. So, I don't think it is up to us. It is up to the mental health profession to do this. Because they are the ones who are helping people in crisis and are going to— You know, it may be that a diagnosis is useful at certain times, and other times it's—you know. At some point, though—I mean, I love—I think it was Lucy Foulkes who talked about this; she's a psychologist in England—but talking about an exit strategy. And no one ever gave me an exit strategy.

So, it was, "Okay, I go to a therapist, and—you know—my wife has left me," or whatever it might be, "and I am in this deep depression. And there's no question. I'm not functioning."

And so, the mental health professional says, "Okay, this is the diagnosis I'm using. You're gonna be— This is the medication I'm prescribing, and in three months we're gonna check in. And if it's good, we're gonna try to get you off the medication. Like, there's always an exit strategy for medication. Not "Here's your medication. You're gonna be on it for the rest of your life."

So, again, like these very different ways of looking at diagnoses. Right now, they're just being given and accepted. And you know, mental health professionals really aren't telling everybody what they need to know, certainly—the people who are like able to be in a position to make those kinds of decisions for themselves.

John Moe: A lot to think about and thank you so much. Sarah Fay is the author of *Pathological: The True Story of Six Misdiagnoses*. We'll have a link to the book, and we'll have a link to the Substack that she mentioned as well.

Sarah, thank you.

Sarah Fay: Thank you so much for having me. This was such a good interview! (Laughs.)

Music: "Building Wings" by Rhett Miller, an up-tempo acoustic guitar song. The music continues quietly under the dialogue.

John Moe: Sarah Fay's book is *Pathological: The True Story of Six Misdiagnoses*. We would love to hear what you think about what Sarah has to say, what your experience is, if this makes you upset or confused or intrigued, or if it makes you applaud in agreement. Our electric mail address is DepreshMode@MaximumFun.org. You can drop us a line there.

We get funding for our show from our listeners. That's how we're able to make a show that goes out into the world and makes you think; maybe helps you a little bit with your mental health; helps you navigate this big, confusing world. The only way we can make that happen is with your financial support. That's the whole model of this show. Please become a member if you haven't already become a member. It's so easy. MaximumFun.org/join. You pick a level that works for you, and then you select our show from the list of shows. And if you are already a member, thank you so much for helping us make this show a reality.

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I want you to know that the 988 Suicide and Crisis Lifeline can be reached in the US and Canada by calling or texting 988. It's free. It's available 24/7. We're on BlueSky at @DepreshMode. Our Instagram is @DepreshPod. Our newsletter is on Substack. Search that up as, you know, Depresh Mode or John Moe. You'll find it. I'm on BlueSky and Instagram at @JohnMoe. You can join our Preshies group on Facebook. A lot of good people there supporting each other, having some laughs, having a good time. I'm there. We'll talk about things. A lot of pictures of pets.

Speaking of pets—hi, credits listeners. When I record my show, I have to remember to close as many doors as possible. That's because we have our two permanent dogs, Sally and Maisie, and one foster dog living with us right now, named Goose. And at any time, dogs are likely to walk on the stairs in our house with their dog nails and make a loud clicking sound. I've had to rerecord many parts of this *(laughing)* closing credits and the opening credits today, because otherwise you'd hear lots of dog fingernails.

[01:00:00]

Maybe I'll stop! Maybe you like the dog fingernails. I don't know.

Depresh Mode is made possible by your contributions. Our team includes Raghu Manavalan, Kevin Ferguson, and me. We get booking help from Mara Davis. Rhett Miller wrote and performed our theme song, "Building Wings". Depresh Mode is a production of Maximum Fun and Poputchik. I'm John Moe. Bye now.

Music:

I'm always falling off of cliffs, now

Building wings on the way down

I am figuring things out

Building wings, building wings, building wings

No one knows the reason

Maybe there's no reason

I just keep believing

No one knows the answer

Maybe there's no answer

I just keep on dancing

Phil: I'm Phil from Pullman, Washington, and I think you're pretty great.

(Music fades out.)

Transition: Cheerful ukulele chord.

Speaker 1: Maximum Fun.

Speaker 2: A worker-owned network.

Speaker 3: Of artist owned shows.

Speaker 4: Supported—

Speaker 5: —directly—

Speaker 6: —by you!