

00;00;00;16 - 00;00;07;28

Steven Molony

Hello and welcome to the very first episode of Chronically Complex, the official #MEAction Podcast. I'm Steven Molony.

00;00;08;09 - 00;00;25;29

Jaime Seltzer

And I'm Jamie Seltzer. I'm a person with ME and ME runs in my family with my mom and sister both affected. I'm the director of scientific and medical outreach here at #MEAction. And I do research at Stanford University on ME/CFS and other chronic complex diseases.

00;00;26;21 - 00;00;48;12

Steven Molony

I'm an actor, writer and filmmaker. I'm also the guy that makes all of #MEAction's videos, and I provide a lot of voiceover as well. I don't personally live with any chronic illnesses, but I have some dear friends who suffer with myalgic encephalomyelitis and other chronic diseases. I want to be a better ally. And I'm looking forward to getting to chat with the truly amazing people we're going to be bringing on to this podcast.

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00;01;28;15 - 00;02;00;22

Jaime Seltzer

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00;02;05;16 - 00;02;10;13

Steven Molony

And now we are so excited to introduce our very first guest, Meghan O'Rourke.

00;02;11;05 - 00;02;44;15

Jaime Seltzer

Meghan is a graduate of Yale University, a New York Times bestselling author, a poet, essayist, and memoirist. She has worked as an editor at The New Yorker, Slate, and the Paris Review. Her work has been featured in The Atlantic, The New York Times, Harvard Radcliffe Institute, The New Yorker, Scientific American, and The Wall Street Journal. Her written works include Half Life, The Long Goodbye, Once, Sun in Days, and most recently, she's put out her brand new book, The Invisible Kingdom: Reimagining Chronic Illness.

00;02;45;07 - 00;03;13;05

Steven Molony

We had an awesome chat with Meghan, and we can't wait for you to hear it, but be sure to stick around till the very end because we've got a very special announcement for you.

<Theme music plays>

00;02;57;22 - 00;03;13;05

Steven Molony

Thank you for joining us for our very first podcast episode. We're excited to have you and thank you for writing such an awesome book is so well-written and I love how just transparent the whole thing is and how vulnerable it is. You know, it's such a it's such a true account. So thank you for that.

00;03;17;20 - 00;03;22;13

Meghan O'Rourke

Thank you. That means a lot. And thanks so much for having me. I'm a big supporter of the work you guys do.

00;03;23;18 - 00;03;24;10

Jaime Seltzer

Well, thank you.

00;03;24;11 - 00;03;24;28

Steven Molony

Thank you.

00;03;25;27 - 00;03;28;04

Meghan O'Rourke

We're just going to thank each other.

00;03;28;13 - 00;03;29;26

Steven Molony

It's going to be an hour of thanks.

00;03;29;29 - 00;03;31;06

Jaime Seltzer

Let's make this the whole podcast.

00;03;31;10 - 00;03;32;01

Meghan O'Rourke

Yeah, yeah, yeah.

00;03;32;08 - 00;03;33;16

Steven Molony

Gratitude is great.

00;03;34;22 - 00;04;02;01

Jaime Seltzer

So let's go ahead then and jump right into it. I have, you know, a relatively complex question, as my first question for you. I was personally struck by our similar backgrounds. I was also raised in New York with two educator parents and had lots of minor warnings about my health when I was small that were interpreted certainly by some of the grownups in my life as being fussy.

And so recently I encountered this line, "Godhood is like girlhood, a begging to be believed." And it just struck me so hard. So my question is, how might health care change if we believed patients, especially women and girls?

00;04;23;09 - 00;04;56;04

Meghan O'Rourke

I mean, it's a radical question, isn't it? It's amazing that it is, but it's a radical question. I think it would be completely transformed. All right. I mean, I think we don't know what it feels like to live in a world where our testimony, especially as women and girls, is taken seriously. And yeah, the more time has gone on on my book tour, the more I have confronted the unanswerability of some questions.

But I think, you know, a very concrete answer would be that it would be a more humane healthcare, would be a health care based on the ethics of listening, the ethics of witness, rather than the urge to prescribe right. Or to dismiss which I think are sort of two parts we often meet as patients. Yeah, a lot more to say about that, but.

00;05;26;25 - 00;05;27;11

Jaime Seltzer

Well, maybe we have time to revisit the question at the end as well.

00;05;30;16 - 00;05;34;23

Steven Molony

Honestly, if you do have more thoughts to expound on, yeah, go ahead.

00;05;35;00 - 00;06;06;00

Meghan O'Rourke

I mean, I think what's wild to me and one of the reasons I wrote my book was that, you know, I had this experience that to me felt profoundly lonely, profoundly isolating, I felt profoundly invisible, which was this experience. Sounds like yours to me of kind of slowly getting very, very sick and really being, you know, incredibly ill before anyone around me believed I was sick, including my doctors, including my family, including even myself in some ways.

It's complicated. In other ways, I really knew something was wrong. And so I think the book was born out of both that profound loneliness and then the shocking realization. That, of course, is so obvious now that I was hardly alone and that there were millions of people like me and that what had felt like my problem, my failure, my strangeness was actually a story being told all across the country, all across the world, and that overwhelmingly most sufferers of things like autoimmune disease were women and tried to follow this thread of what did that mean?

Why did this happen? Why was it happening? In an age where it's so easy to get a diagnosis for so many things? Why were millions of women incredibly sick and going on that I heard and I think the answer has to do with healthcare's desire to have things look really, really clear cut and measurable. And it's historical pretty much complete lack of interest in women's health to the extent that they've just started really researching how biologically female people respond to certain drugs. Right. Or how Ambien affects us differently from anywhere. So yes, we can talk for an hour about this.

00;07;32;24 - 00;08;11;15

Jaime Seltzer

But I mean, that's that is why we're here. I was right, though, that as you were talking, I had the thought isn't that interesting that that's one of the themes that pops up in these stories so often? I remember Jen Brea saying exactly the same, that it was a profound realization that she wasn't alone in this and I thought, isn't it always the story of marginalization, that isolation is half of the story There's almost a cultural push for us to believe that we are unique and alone and strange, and that therefore we don't deserve the attention to our suffering that other people do?

00;08;12;08 - 00;08;39;20

Meghan O'Rourke

Yeah, absolutely. And I will say also of myself, Jaime, that I don't think I was very sympathetic to the people I had encountered in my life who were sick as a pretty young person and a teenager. So teenagers, I guess, are solipsistic in some way. But, you know, I think a lot now about a friend of mine, a really good friend of mine, her mother had ME/CFS, and it was just impossible for me to grasp as a 17 year old.

I don't know that I was unsympathetic, but I didn't try very hard to understand her. Her reality And I think that you know, again, when I think about what this book is, it's not a memoir, right? It *is* a memoir. It has my story in it. But it's, for me, more than a memoir because it's really the account of a kind of radicalization that I underwent in which the very terms in which I had understood my existence in so many ways got turned upside down.

And one of those terms was that I really went from, you know, thinking about my individual life and thinking I had some control over it and control over its outcomes to recognizing a kind of radical vulnerability and also recognizing that everything about my health was intimately connected to other people's health and well-being and to our medical system and to our health care and to our food system and to the research that has or has not been done right, that in fact, everything that felt individual and isolating was a sign of my interconnection with others and how we had tended to one another or not, in this case, social creatures.

That's a very abstract answer, but I hope that makes sense in some ways.

00;09;58;00 - 00;10;25;28

Jaime Seltzer

Yes, it's not abstract at all. It just makes me think that should be our experience of growing up. Right?

And some people simply do not You know, when you describe a lot of teenagers are self-absorbed. Well, we have to be at that age, right? We're trying to tend to our development and everything feels so immediate and so challenging at that age.

But as we grow older, we should be able to expand our frame of vision and others and understand that we all live here together. We all affect each other.

00;10;37;07 - 00;10;55;12

Meghan O'Rourke

Yeah. You know, it's really interesting to me, at least that I have two very young sons who are five and three, and they're the people who see my illness most clearly. And often I'm asked about how I talk about it or how I keep it from them. And my answer is I really can't keep it from them. They see it, they feel it.

They are the most open to it and most interested in it. Right. Because they haven't learned, I don't know, to avoid it, to look away or to normalize it. Right. It's their mother, but it goes beyond me. It's just their porousness to the world and their care for other people.

00;11;16;19 - 00;11;30;12

Steven Molony

That was a really touching element in your book. Your journey of motherhood amidst this sickness and everything. Your journey of motherhood through it all was really touching. So thank you for that as well.

00;11;31;27 - 00;11;49;11

Meghan O'Rourke

Thank you. Yeah, it's, you know, it's a tough one, right? And I remember and I still I'm scared about it sometimes. I remember before getting, you know, I wanted to have kids when I was really sick. And I remember just thinking, this will kill me if I do this. And in fact, I had to get much better before I did.

But even though I'm doing pretty well now, it's still a challenge, you know, to be someone who's struggling with their health, you know, having kids is sort of an untold story in its own right.

00;12;00;29 - 00;12;29;06

Steven Molony

Yeah. You know, for me, I related very much to that part of the book where you were saying that doctors don't often want to admit that they don't know, that they're unsure.

And for me, you know, I grew up believing that the doctor knows best and the doctor knows all. And sort of similarly to that first realization that you have when you realize like, "Oh, my parent isn't an immortal superhero," — the first time that you realize that the doctor doesn't actually know everything, it's terrifying, really. You know, it makes you feel vulnerable and exposed. What would you say was— when was the first time that you had that realization yourself?

00;12;48;23 - 00;13;19;21

Meghan O'Rourke

Oh, that's such a good question. I feel like it crept on me slowly, like someone's sinking into ever deeper water. It didn't really crash over me like a wave so much as slowly I began to realize it. And like you, I really was raised with a full faith that doctors, my parents were baby boomers. They were Irish. They came from very traditional Irish Catholic families in New Jersey, you know, and it was just like my mom went to— I had all these little things as a kid, as Jaime was saying.

And I would go to the doctor and be like, my knees hurt, my chest, my ribs hurt, my back, growing pains and so then I would say to my mom, everything's hurting. And she's like, it's growing pains. Just go to the doctor about it. And she'd give me an aspirin. Right. She wasn't totally unsympathetic. But there was this way in which it was just case closed.

Like if I fell, we went to get an X-ray. But when I complained about various things, I had terrible allergies. So bad that I would be coughing blood. It was kind of just like, Oh, well, it's this. And so I think that— and I mean, I love my mom she's an awesome mom. But there was just this very particular relationship to your body in which unless you have a really clear problem, like a broken bone or strep throat, in a way we were not fussed over.

Right. We were appropriately taken care of for things like that, of course. So I think it took me ages as a person in her twenties, which is when I really started getting sick, just to be able to even believe that what the doctor was telling me was not true. So I would go and say, something's going on. I'm extremely tired all the time. I can't think of words. And they would say, you're probably a little stressed. And I would think almost in relief, right? Because the illusion of control, like, oh, maybe I am just a little stressed. So just go to sleep earlier and I'll work a little bit less and I'll take a long walk. And then I just didn't get better.

So there wasn't one single moment. But I think what happened was that eventually it became so clear that something was wrong and really that took the form of just excruciating neurological pain that was overwhelming to the point of almost unbearable to live with that it was really bad that I just thought, well, I can't value what the doctor is saying. Their dismissal of my testimony because I'm really on the verge of not being able to live like this anymore.

00;15;17;23 - 00;15;21;22

Steven Molony

Yeah. I mean, it kind of gives you this feeling that you're on your own.

00;15;23;08 - 00;15;45;25

Meghan O'Rourke

Yeah. And I think it was really scary. I think I wanted to believe the doctors were right because then I didn't have to face the facts that something was really wrong with me. And also, more terrifyingly, that something was wrong with me that they didn't understand. That's such a-- I've been talking to people in the past weeks who are really at the beginning of their journey with-- journey is the wrong word.

You know, it's a little too hokey and overused, but it is a journey, I guess, of their illness. And I just I get this pit in my stomach when I remember those first months of being really, really sick, I'd gotten a virus and I went really downhill. And just that sense of overwhelm, of exploring the Internet and being like, oh, my God, my microbiome, these viruses, I have my, you know, autoimmune disease it was just like, where do I even begin, right?

How do I even begin taking the clues that were in my lab work and realizing that I was going to have to piece together the larger narrative or somehow pull the needle out of the haystack and find that doctor out there who could help, which, as we know, is really, really hard to find.

00;16;32;02 - 00;16;45;18

Steven Molony

Yeah. Your journey about finding your way to the diagnosis of Lyme disease was a roller coaster. I mean, you know, even people thought you had ME for a while there, too.

00;16;46;24 - 00;17;18;27

Meghan O'Rourke

Yeah. No, I mean, I think I've talked to different people who have different viewpoints. But, you know, yes, a doctor diagnosed me with CFS.

Another one that said, oh, you have something like ME/CFS. In many ways I met the criteria for it. My problems, neurological and just extreme fatigue and brain fog. And I don't know, you know, post exertional malaise and all of that which continue to be the ongoing things that I suffer from just more mildly.

But it was a total roller coaster of kind of having to tear down. I think one thing maybe people don't realize, if they're not chronically ill with these kinds of poorly understood diseases, or something like ME/CFS, which is so under-researched or chronic Lyme disease also and the research that, you know, to build a life with a diagnosis like this is to, in a sense, have to dismantle everything you do and rebuild a totally new system of understanding, not just of yourself, but of the world and of medicine and of friendship and all of this.

And that's what that period when I got really sick and was searching for the diagnosis was this period of radical dismantling and rebuilding.

00;18;05;21 - 00;18;21;28

Steven Molony

Yeah. It seems like you had a pretty good supportive circle of people around you, friends that understood and people who were there for you. Did you experience any kind of fallout where that wasn't quite the case?

00;18;23;10 - 00;18;44;10

Meghan O'Rourke

Yeah, I think I was pretty lucky in that my husband, he's actually my partner, not my husband. He always believed me, you know, he didn't necessarily give me what I felt I needed to write because I think sometimes when you're sick, you have a lot of need and a lot of anger and frustration at certain points and a huge amount of grief.

And there is a loneliness to all that. But even he can penetrate. But I was really grateful that he was one of the first people to look at me and say, you know, something really is wrong. We've got to get some answers. But there were plenty of friendships that, you know, I had. Yeah, but it alienation occurred a sense of, I think some friendships.

I was young, I was in my early thirties when I got really sick. And I think for some people it was just too scary and too hard to deal with. So there was a lot of you look great, you look fine, you're doing fine. There was a lot of reassuring me. Right.

And I think one thing I try to write about in the book is that if you are the companion of or the friend of someone who's chronically ill or a caretaker, that, you know, that false reassurance may not be the thing that's needed. But that those of us who are living with these conditions really know the ins and outs and the reality of it in some ways. And I think often what I wanted was someone just to listen and mirror rather than to tell me that I looked fine and I was still doing it. So yeah.

00;19;55;04 - 00;20;06;07

Steven Molony

That's why I love that title, *Invisible Kingdom*. I think that's perfect because, you know, there's plenty who look perfectly healthy, look perfectly fine, but still waters run deep, right?

00;20;07;05 - 00;20;30;18

Meghan O'Rourke

Yeah. You know, and I think if you have a lot of neurological problems, which I did and still have some, I became very adept at hiding them. And I even at my sickest, I was able to go and teach the one class I taught and kind of muscle through it. And then I would come home and I would pretty literally collapse.

You know, I would collapse on the train and Penn Station, the conductors would have to wake me up. I was just so out of it and get me out the door and I could get home and then I would be bedridden for days. But the people who saw me on that day just saw that I was there teaching my class.

They didn't see the rest of it. I didn't show it to them because I think I was scared to be fully open. And there were people I talked to, but other people where I felt, well, professionally, you know, what if I lose my job? What if I lose future professional possibilities, right? But the point being that you do become adept at hiding things sometimes there's a stage in your illness where you can hide.

And I think maybe a stage where you can't when you get really sick, you can't hide. But I think a lot of my experience of being ill, I was only capable of hiding for brief periods of time. And so part of what I try to interrogate in the book is why I did that, why others wanted to let me do that, right, and all of the things that go into making us visible. And then I think also for the title, I really wanted to convey that moment to realizing I wasn't alone, that there was many of us, and that there's perhaps a certain possibility in that many rights organizations that are doing advocacy work and channeling and helping make change.

00;22;01;18 - 00;22;27;27

Jaime Seltzer

You know, that brings me to the idea that you challenged some mainstream beliefs and perceptions about illness in the book and very astutely. So what of your own perspectives or beliefs do you feel were the most challenged over the course of your research and writing as you were putting this together? Was there anything that you were coming up against in yourself.

00;22;30;04 - 00;22;31;14

Meghan O'Rourke

Such a good question.

I have two answers. One was more about how I navigated illness, and I don't know if this is what you mean, but I think just the number one thing that I struggle with is the ways in which even though I know better, I still want to try to control the outcomes, right? I still want to feel that I can change it or affect it even as I come to know that I'm living with the illness instead of overcoming it, right. But I think the most intellectually challenging piece in the piece, I still really don't have a soundbite answer. Certainly is the sort of question of mind and body, to put it too crudely. Right, that I really resisted when people asked, you know, sort of certain point of my illness, some of the people around me basically began to suggest that I was the cause of my own illness because I was type-A, stressed, high functioning.

And a lot of people sent me to the work of John Sarno. I did not feel this way, but I had a lot of body pain. I now have a syndrome that I didn't know that at the time. So people are conflicting, like, oh, do John Sarno's work and exercise your resentment and your repression and you'll suddenly feel better.

And I faithfully did it all. I did everything. It did not help. Didn't help my pain at all. And I think-- so I was super resistant to this idea that, you know, for good reasons, I really want to resist. And the book resists the, kind of, what I see and what I describe in the book as an oversimplification in which I think what's happening is that healthy people are so threatened by the possibility of illness and it feels really random, right? But young people just suddenly get very sick for reasons they don't understand, can't really see what's wrong. This is what happens in the popular narrative with these illnesses. And so they want to sort of think it's all controllable and tidy by assuming that it's in the sick person's head. Right. It's a way of letting themselves off so anyway, I really resist a lot of it.

But at the same time, there's some really fascinating work about the ways in which our nervous system and immune system are deeply entangled and I think that there are mysteries there. There is some mystery in terms of how our perception of threat and stress and trauma affects our immune system long term. But what I want to be really careful to say is I don't think that is the cause of these illnesses right I think it's a complicated factor that's really hard to talk about.

It demands nuanced discourse and sensitivity of that. Sadly, we often don't have. I don't know if that resonates for either of you or, you know, what I'm talking about.

00;25;36;08 - 00;26;07;27

Jaime Seltzer

Oh, that was my very next question, madam. So, yes, about the mind body push pull and how because these diseases have been misrepresented as psychological in the past. You know, sometimes people even struggle to say stress. It does make my presentation worse because they're afraid that people will then conclude that stress has caused their illness and that if they were less stressed, then they would no longer be sick.

And of course, that's a vast oversimplification of the reality. And yes, we are all aware of cortisol and epigenetics and all that fun stuff that shows that your environment actually affects the body.

00;26;22;24 - 00;26;23;16

Meghan O'Rourke

Shocking.

00;26;23;17 - 00;26;53;29

Jaime Seltzer

I know, right? It's almost as though we are one organism on a planet with lots of other organisms. And everything interacts. But I think that that also does get to, you know, what we've been talking about, which is that the reality is complicated and we prefer simple answers to direct questions even when that's not available or not logical. We will pretend it is in order to feel more comfortable.

00;26;55;10 - 00;27;23;09

Meghan O'Rourke

I mean, you hit the nail on the head. I can't say it better than that. We prefer simple answers. And, you know, I think it's really scary too, you know, I try to be generous in my thinking sometimes. Right.

And sometimes, you think, why is it-- I mean, well, I guess another way to put it is a real question for me that I try to answer in my book is why is it so hard to recognize other people suffering?

Why is it just so hard? Right. And I talk in the book to a friend of mine who's a sort of he's a moral philosopher. He's at Oxford. And he says to me, you know, not literally him about me, but he says it's because your suffering puts a burden on me. That the act of recognition is actually burdensome and requires effort and Hermione Lee-- I think it's Hermione Lee-- in her introduction to Virginia Woolf's *On Being Ill* has a similar-- talks about this, too. I think Woolf even talks about it, about, you know, the effort of recognition could take up our whole working day. Right. And I think that for some people, they just don't want to make that effort. Right. That's really abundantly clear that they would just be happy if all chronically ill people just went away and I think for other people it's actually painful to make that effort, but we got to make that effort. It's got to change the conversations somehow.

00;28;20;06 - 00;28;24;21

Jaime Seltzer

I can't let you say any of that without making the joke that this is why nobody likes moral philosophy.

00;28;26;17 - 00;28;52;16

Steven Molony

I listened to the audio book version of your book, and I remember listening to that part and thinking like, wow. Putting myself in your shoes, if one of my friends was telling me that, I'd be like, what? That would be a tough thing for me to hear from a friend, you know?

00;28;52;27 - 00;29;14;14

Meghan O'Rourke

Yeah, no, I can't lie, I got kind of mad at him. Even though actually one reason he could say to me is he does live in the land of moral philosophy, but also he's a really good friend. So he was able to theorize in a way that I think someone else who did look away from it wouldn't have even been able to articulate that to me, probably.

00;29;17;02 - 00;29;43;26

Jaime Seltzer

A lot of our barriers, though, right, a lot of our barriers are around this idea that people have run out of empathy and they're spread too thin.

And ignoring the fact that there are chronically ill people and that they at any point could become chronically ill, that there's nothing magical or mystical that protects them is very psychologically challenging to take on board, I suppose.

00;29;43;26 - 00;30;08;14

Meghan O'Rourke

Yeah, yeah, yeah. You know, exactly and I mean, it's been so interesting sort of the mask discourse, right - I've been involved in it on social media and writing about it and it's just fascinating to see the real range of responses because you realize that people are so exhausted that they are willing to say, like, "I just don't care. I just don't care about your reality."

00;30;13;01 - 00;30;14;19

Jaime Seltzer

Or "I reject your reality."

00;30;14;28 - 00;30;42;23

Meghan O'Rourke

Or even "I reject your reality. And in fact, I would be fine if you got sick and died." Right? I mean, it's a whole-- and I've gotten those responses from some people. You know, and I think that's part of the work is, I don't know, just recognizing that range that's out there. And then I think, you know, someone asked me recently, what do you do about those people who say, I would be fine if you get sick?

And I think you can't actually focus advocacy or conversations on those people. Right. Because they're never going to be shifted. But the optimist in me thinks that there are a lot of people who don't understand very much about the reality of chronic illness, who maybe aren't so dug into a position but are just trying to live their lives and haven't had that proximity or are scared by it or all the things you've just articulated. And so my hope is that some of them are the people we can reach and change, change the minds of but to do something, there's--

00;31;25;03 - 00;31;26;05

Jaime Seltzer

I also think that there are-- I'm sorry, go ahead. Go ahead.

00;31;26;16 - 00;31;42;21

Meghan O'Rourke

I was just going to say, I think to do that, that's why we need research right?

And why we need medical education, because we need the frameworks to come from science. And then I think people do latch on to science. And it's like we understand now that not all cancers are the same that lymphoma is one kind of disease and breast cancer is another, right. And the more knowledge there is, the more the frameworks get accepted and popularized in ways that create shorthands for empathy. Sorry, what were you going to say?

00;31;54;18 - 00;32;11;18

Jaime Seltzer

Oh, I was going to say that I do believe that people who are genuinely okay with lots of people dying and not just saying that as a way of saying, "I don't want to talk about this anymore, my brain is full." I think that those people who genuinely don't care, that number is very small.

00;32;11;28 - 00;32;12;29

Steven Molony

Yeah, I'd like to think so.

00;32;12;29 - 00;32;45;22

Jaime Seltzer

I do think so. I think that we have let those voices get very big on social media and I also think that bots are a genuine phenomenon. And they often are pushing what we would consider to be anti humanist rhetoric. Some people are worth more than other people. And, and all of that is not necessarily something that your average Joe on the street is walking around genuinely having thought about and genuinely having like a deeply held belief.

00;32;46;03 - 00;33;05;02

Steven Molony

And also, you know, what does that say about those people? If they-- if that is how they genuinely feel, then they clearly have a lot to work through themselves - that they're just is no more room to hold space or empathy for other people. If that's the worldview that's adopted, that is literally just like, "I don't care. Live or die. Whatever, good luck." Like it's just-- I don't know. They've clearly got a busy plate themselves, right?

00;33;10;01

Meghan O'Rourke

Yeah.

00;33;11;12 - 00;33;46;07

Jaime Seltzer

But it's also like a rejection of that idea of interconnectedness. Which speaking of masks, right, there's this idea going around now that it's all about your personal choice. Your personal choice can't kill someone and still be your personal choice. You can't choose to infect somebody with SARS-CoV-2 and have them die. That's not up to you. So a lot of it is a rejection of the idea that we have to consider everybody and that if we didn't consider everybody, society would not be society.

What's the point of gathering together in bigger groups if we're not here to help each other? Why not just live alone in a cabin in the woods and like grow your own carrots if the main assets of society are not available to everybody?

00;34;01;15 - 00;34;45;06

Meghan O'Rourke

Yeah, it's funny, I've had this thought that in a way, the experience of the pandemic for American society or any society, but maybe particularly American society is a little bit analogous to the experience of becoming chronically ill. Which is to say that to openly and rationally live through the pandemic, I think, is to acknowledge that an agent of change has entered our lives and pretty radically shifted our sense of what was possible, our sense of what these last years would be like, a sense of even what the next five or ten years might be like, and to accept a kind of radical vulnerability and uncertainty into life, right. To really live with the pandemic is to do that, not least because even with the vaccines, we now know that the virus can trigger all kinds of long term problems in a portion of the population. And we don't know who. Right? And my experience of getting chronically ill was-- and I think the book, the shape of the book-- because I spent a lot of time being like, how do you write chronic illness, right? How do you make - I'm a writer - how do you make a story out of what isn't... resists tidiness, resists conclusion, insists on its own ongoingness and surprise and is repetitive. Right. And you know it was a really boring first draft that I wrote but interesting to me. Important to me. But I thought a lot about how do you pull the reader in.

And I think that the answer I came to is that I have to take them on the journey, the quest, the experience of being kind of radicalized by uncertainty and by having the life I thought I was going to have really disappear, losing pretty much a decade of my life the way I thought it would be experienced - just gone. My thirties should have been a great decade. I hear it's a good decade.

00;35;59;18 - 00;36;01;19

Jaime Seltzer

I hear the same. I never got to figure it out.

00;36;02;00 - 00;36;04;08

Steven Molony

The Yelp reviews are great about the thirties.

00;36;04;21 - 00;36;27;25

Meghan O'Rourke

Not so great for me. You know, and I think that experience of, I don't know, letting go of certain kinds of narratives and allowing for uncertainty to come into your life is a really hard one. And I think that's what pretty much anyone who's living with chronic illness has to do. And I feel like that's what the pandemic has asked of America. We've seen that some people do it and some people are still fighting the reality.

00;36;33;00 - 00;36;57;11

Jaime Seltzer

Or they started to fight the reality once tribalism came into play and they were given permission to do so by their in-group. But yeah, that's, that's actually a very astute observation. It's like the whole world got to experience what it was like to have this tumult of you never know what's going to happen to your health tomorrow. You're going to have to change your behaviors and your work life and social life are going to radically change. And some people did throw themselves on the ground and kicked up a little fit. They just wouldn't. We do have some more straightforward questions. If you're ready for a few softballs, Meghan.

00;37;20;09 - 00;37;25;09

Steven Molony

Yeah. Obviously what we're talking about here and everything surrounding this is all heavy stuff.

00;37;25;13 - 00;37;25;22

Meghan O'Rourke

Yeah.

00;37;25;25 - 00;37;37;08

Steven Molony

But there was a few times throughout your book where a definite tone of humor was coming through and one, what were the fun parts for you of writing this book and going on this journey?

00;37;38;21 - 00;38;03;11

Meghan O'Rourke

Yeah, I don't know if any of it was fun, but a very beautiful and very loving review-- or positive review in The New York Times did say there weren't enough jokes in it. Of course, you know, I ignored all the positive excellent praise. The book got and thought a lot about that one line. And, you know, I did think about the fact that I think when you're chronically ill-- because his point was an interesting one, he said, you know, even people who write memoirs of dying often have a kind of mordant wit. But there's not a lot of funniness in this book. Now I, like you, think there are some funny parts. I do think there are. But I thought pretty seriously about that critique because it made me realize something, which is that when you're dying and it's recognized that you're dying and you know what the disease is, you're kind of in that experience sometimes of even a galvanized sense of "this is it," right? Even cancer patients-- my mom died of cancer, my dad died of cancer related complications, like they had periods where they felt okay and they-- it was like they sucked everything out of life. They knew it was going and they sucked the joy. They sucked the humor. They also suffered, right. But it was in the room. But actually thought his point kind of made my point for me, which is that chronic illness that goes unrecognized is this flattening experience that the lack of recognition robs you of that possibility of finding humor and joy because you're fighting so hard to be like, "This is happening," right? "Please see this, please research, please treat it. Please honor the dignity of my suffering."

But I think you're right that there are some funny parts in the book. And I will say that as I have been lucky enough to have had my illness recognized and to get a series of diagnoses because I actually live with several health conditions that are interconnected, you know, I was able to look back with some rue and some, you know, desire to find those moments of just, "Oh my God, can you believe this," right?

And I think with the book, I was really wanting it to be like a good companion to other people who were sick. And I was like, I want to make them laugh. Sometimes I want to be that person who's like, "And then, if you can believe it, this is what this is what happened."

00;40;02;05 - 00;40;03;18

Steven Molony

That really came through for me.

00;40;04;17 - 00;40;06;13

Meghan O'Rourke

Yeah, that's good. Yeah.

00;40;06;14 - 00;40;27;26

Jaime Seltzer

I used to have a very good friend who said to me, "Why do you always laugh when things go wrong?" And I kind of thought to myself that chronic illness is the training for that. You laugh when things are absurd and things are so far beyond what you would expect to happen, that the absurdity and the uncertainty catches something in you and you laugh. And I said being chronically ill had trained me to laugh when things are ridiculous, especially when things are going wrong, and ridiculous.

00;40;36;23 - 00;40;40;24

Meghan O'Rourke

Right? There's a moment where you just believe it. What are you going to have to do? You have to laugh.

00;40;40;29 - 00;41;00;28

Steven Molony

Yeah, there's a breaking point where everything is awful and then suddenly you punch through and you find some levity. Because I feel that that's important in everyone's life, you know, to find those moments of humor and especially especially when you're reflecting on it, you're able to look back on it.

Jaime Seltzer

Or they find you.

Steven Molony

Yeah. Or they find you, that's right.

00;41;00;29 - 00;41;01;26

Meghan O'Rourke

Yeah. Mm hmm.

00;41;02;01 - 00;41;28;19

Jaime Seltzer

Well, let me ask you a practical question, which is-- this was asked of me yesterday, and it's just a total chance that it was the question that I intended to ask you. How did you manage living with your illness and writing this book or doing this work at the same time? And I won't necessarily ask you to get into the specifics of your daily schedule or anything like that.

But for people who are thinking about-- especially Long COVID folks, right? They're newly ill, most of them, and they're trying to think, how am I going to manage work and how am I going to manage maybe the advocacy side of things like I want to be able to fight for people like me. How do I handle it?

00;41;49;29 - 00;41;51;28

Meghan O'Rourke

Yeah, such an important question. I like to be really transparent when I talk about this. So writing students ask me this a lot because in writing programs I've taught for a various number of days were always telling the students, Not me anymore. But some of my wonderful faculty friends, understandably, are like, "You're here to do this. Do it every day. Work really hard and just keep powering through, powering through." And I had a chronically ill patient student reach out to me. She said, "I can't and it makes me feel really bad and that I'm like a failure when I hear this, like, 'Get to your desk every day,' and it's just like there's just days where it's a struggle." And I said to her, look, you don't work those days. You just can't.

And you actually have to forgive yourself. You have to accept that reality. So the first thing I like to say is that when I was at my sickest, there is no way I could have written this book. Absolutely no way. I could barely write a sentence and so I know I'm sitting here today and I'm speaking in paragraphs, and I sound cogent, but I at certain times could barely talk. I had a lot of neurological problems. I think, again, my presentation really overlapped with ME/CFS presentations of some kinds and I-- tremendous executive function, memory loss. I'm sitting with a friend I've known for years, driving him home, looking at him and being like, "I have no idea who this person is," with that level of dysfunction. So when I was at my sickest, writing had been my way of coping my whole life for anything. And so I told myself, okay, all you have to do is write one sentence. So I think if you're struggling with wanting to own some part of your identity, but you're really sick set a very small goal for yourself, right? For me it was a sentence. Just write one sentence my a story about like 15 minutes a day where I had enough presence of brain function to do that.

But I knew that I couldn't start the book. It was just beyond me. And it was really not till I got in some treatment and was really living with illness at a slightly different level that I began the research and the collecting and the writing and one thing I knew was that-- or one thing that made the book take a long time is that my cognitive function, you know, I don't go out talking about this too much, but it's still spotty. And so details, information, things that once I used to have a very good memory.

But, you know, I used to read something, retain information, know who said what, I had to just do so much fact checking on this book because I knew that I was going to have sort of misconstrued things. And in fact, the fact checking was a little bit heartbreaking to me personally because it was this experience of realizing that I'd just gotten things suddenly... not even wrong - I thought I was saying them clearly, but I said them in a really mixed up, muddled way.

So I think the first thing is it's a marathon, not a sprint. Right. Really taking care of yourself, really recognizing that the way you work is the way you work. And however anyone else works, it's not going to be your way I have to come to a point where I just don't try to work on the days when I have really bad brain fog.

I started this book in 2013. Finished it in 2021. My friends were finishing books every two years. Right. And that was just the reality. It just took me longer to do that. And in moments I thought it would never be done. But I sort of inched forward. The other thing that's really important is that some work you can do lying down.

So I think most of this work I did lying down, I had pretty bad POTS for parts of this book, I have dysautonomia. I can lie down and get a few good hours out of the day on some of my middling days. But if I had a job, by the way, where I have to be on my feet helping customers or you know, I always like to go back to this basic point, which is some of us are really lucky and the work we do, we can do lying down. So I try to focus on positive stuff like that.

00;46;01;02 - 00;46;10;15

Jaime Seltzer

Yeah, and I absolutely agree with you about just not working when your brain fog is but so bad. I've gone back on-- when I've forced myself to, I've gone back and looked at that work and been like, "Oh no..."

00;46;10;23 - 00;46;20;01

Meghan O'Rourke

You know, I had just wrote about a hundred pages - I'm not kidding - that I've written during these brain fogs. It was pointless. And so I stopped. I just stopped.

00;46;20;04 - 00;46;23;20

Jaime Seltzer

It's better to just rest, you know, and wait until you're a little sharper.

00;46;24;14 - 00;46;33;00

Steven Molony

I think that's such an important reminder. Was there anything that surprised you or that you learned along the journey of writing this?

00;46;33;29 - 00;46;59;10

Meghan O'Rourke

I think, yeah. I think one thing that really surprised me was really realizing that... You know, I think many of us who have conditions like CFS or post treatment, Lyme Disease Syndrome or long COVID are kind of avidly researching and learning a lot about our conditions. And then I don't know if you're like me, I would learn a lot and be like, wow, this is fascinating, I'm starting to have an understanding of what might be going on. And then I would doubt myself because I would think, well, I'm not a scientist or a... you know, if I can acquire all this knowledge, why is my doctor just like dismissing this, right? And so I would doubt myself. So I think one of the really interesting things about the book for me, which is maybe obvious to you all and everyone listening, is that when you start talking to the researchers, the researchers totally get it. The good researchers are like, "Yeah, of course. And dah, dah, dah, dah, dah." Right? And so interviewing researchers was a really important piece just emotionally for me. Of healing. Because it was like when I talked to them, they were speaking my language and they were helping me make sense of things that I had picked up in a piecemeal way as a journalist and saying, "Yeah, you're right about that. And here's this. And read this study, and read this and here's the framework for understanding that." But that information just hasn't made it downstream to your average GP, your average neurologist. Right. And so I think that was a really fascinating part and it gave me hope because the knowledge is out there getting slowly acquired. The science is super complex. There's a lot to know. But what I was seeing and thinking about, yeah, there were other people who are way better at this. Who are scientists.

00;48;15;26 - 00;48;34;29

Jaime Seltzer

Well and you know, it takes a while for information to trickle down because it's different if you have a hypothetical theory and you have some decent support for it, you can begin believing it may it may be possible that this is true versus now I'm going to use that knowledge and apply an intervention on a patient and potentially affect their life. So it takes more for clinicians to feel certain.

00;48;38;17 - 00;49;13;20

Meghan O'Rourke

It certainly does. And I don't mean to-- That's such a great point. I don't mean to make light of that, but I think it was helpful to me on a personal level to be like, "Right, maybe some days we'll get to that place where we've got that evidence and that data." But in terms of surprise, I think realizing, you know, this has been our theme the whole time, which is how many people were going through this and how many people are experiencing, you know, dismissal from some doctors and that was really, I think, heartbreaking to see.

And I if I have one piece of hope about Long COVID, it's that so many medical professionals are going through some version of this or know someone who's going to some version of this. But I think there's a cracking open or at least compassion and realizing that they need to rethink.

00;49;29;07 - 00;49;31;23

Steven Molony

Yeah, I hope so. I think so, too.

00;49;31;23 - 00;49;49;17

Meghan O'Rourke

Yeah. Yeah. You know, not everywhere. Right. We've all heard the stories, but I hearing it from people when I report on-- I talk to doctors and physicians. And I think the biggest problem is actually systems, systems and how they make it hard for individuals to make change.

00;49;50;18 - 00;50;07;07

Steven Molony

Yeah. Well, hey, thank you so much, Meghan, for coming on with us and chatting with us today. We really appreciate you taking the time and again, excellent work. I love the book. How would-- where would people go if they wanted to buy this book?

00;50;07;16 - 00;50;28;10

Meghan O'Rourke

Yeah, they can go to any-- great to support independent bookstores by going to bookshop.org I believe it is called, or of course Amazon, other big retail places. Your independent bookstore and your local bookstore should have it. Or if you ask them for it, they can order it for you. Yeah, yeah.

00;50;28;24 - 00;50;29;10

Steven Molony

Awesome.

00;50;29;12 - 00;50;32;16

Jaime Seltzer

Thank you so much, Meghan. Thank you for chatting with us today.

00;50;33;07 - 00;50;38;13

Meghan O'Rourke

Thank you. And we even got a joke or two in, I think too. But thanks so much for having me.

00;50;38;17 - 00;51;09;14

Steven Molony

Of course. This was-- as a quote unquote "healthy person" - I'm sure there are some folks running around some gyms who would contest my claim to being a "healthy person" - but as a as a healthy person, this kind of stuff is important to me. You know, it expands my awareness and my education it makes me a better ally and it makes me able to, I don't know, just do better work for #MEAction in general, so I am grateful for your work.

00;51;12;03 - 00;51;25;01

Meghan O'Rourke

So great. That means so much to me. And I just-- #MEAction is doing such awesome work. And if I can be an ally and support you guys and if you and Jaime have thought-- just reach out anytime, whatever I'm able to do, I'll try to do.

00;51;25;01 - 00;51;31;16

Steven Molony

Awesome. Well, yes, again, thank you so much for your time. I'll let you go and have a great rest of your day.

00;51;32;03 - 00;51;33;07

Meghan O'Rourke

You too. Take care.

00;51;33;25 - 00;51;34;28

Steven Molony

Thanks, Meghan. Bye bye.

<Theme music plays>

00;51;39;01 - 00;51;41;27

Steven Molony

Thank you so much to Meghan for joining us on the podcast.

00;51;42;10 - 00;51;47;06

Jaime Seltzer

And thank you again to our sponsors at Outside in Theater and the Goodman Center.

00;51;47;18 - 00;52;13;15

Steven Molony

Remember when I said to stick around till the end? Well, this is it. We've arrived. Megan was kind enough to offer up a giveaway of her new book *Invisible Kingdom*. To enter, give us a rating and leave us a review on Apple Podcasts or Spotify. Then let us know via email, at podcast@meaction.net. We'll be choosing two lucky winners at random, and then we'll follow up with you and have a copy of *The Invisible Kingdom* sent to your front door.

00;52;14;26 - 00;52;26;11

Jaime Seltzer

At #MEAction, we're building a global movement to fight for recognition, education, and research so that one day all people with ME will have support and access to compassionate and effective care.

00;52;26;28 - 00;52;36;18

Steven Molony

If you'd like to stay up to date with what we're up to, visit us at meaction.net. Subscribe to our newsletter and follow us on social media @MEActNet.

00;52;37;13 - 00;52;54;06

Jaime Seltzer

If you have any questions or suggestions for guests you would like to see on the show, feel free to email us at podcast@meaction.net. Thanks for joining us at #MEAction's Chronically Complex podcast. Keep reading, writing, speaking out and speaking up.

00;52;54;13 - 00;52;57;22

Steven Molony

And don't forget to #StopRestPace. We'll see you next time.