

MCS & TILT: Chemical Sensitivity in a Toxic World With Aaron Goodman

SPEAKERS

Kendra Seymour, Aaron Goodman

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Aaron Goodman

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You know, living with this condition means, you know, every day is, is an unknown, like, I try to control my environment. You know, my home, my home is, is really safe, you know. But the moment I walk out the door, I'm often exposed to chemicals in the air that I that I inhale, that make me really ill.

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Kendra Seymour

00:20

Hello and welcome back to Your Indoor Air Podcast brought to you by Change the Air Foundation. My name is Kendra Seymour, and today we're diving into a topic that affects millions of people but is often misunderstood: multiple chemical sensitivity, or MCS for short, and toxicant induced loss of tolerance or TILT. Now for those living with MCS and TILT, everyday environments filled with fragrances and cleaning products and other chemicals, most people don't even think twice about can trigger a wide range of symptoms, and many of them can be debilitating. Now, despite its serious impact, MCS and TILT remains widely unrecognized and is difficult to diagnose. To help us better understand this condition I'm joined by Aaron Goodman, who is the founder and host of The Chemical Sensitivity Podcast, which we are going to link to in the show notes. And the aim of his podcast is to amplify the voices of people with multiple chemical sensitivity and research about this illness. Aaron has lived with this condition, also known as chemical intolerance, toxicant induced loss of tolerance, idiopathic environmental illness for years. He is a long term journalist, communication study researcher, educator, and lives in right walk, excuse me, White Rock, British Columbia, Canada. So thank you, Aaron, so much for joining us.

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Aaron Goodman

01:07

Thanks so much for having me. Kendra,

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Kendra Seymour

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I've really enjoyed listening to your your podcast over the last year or so, and really appreciate everything that you're doing to shine a light on this, because I think it not only is there not enough awareness out there, it's so poorly misunderstood and it's so life changing that I think if this is something you're experiencing and you're listening, it can feel very lonely at times and so I love that your podcast really offers that community, that connection for people, so they feel heard and seen, and they can connect with the latest research. So we're going to talk about some of that today, right? That we're going to get into the difference between or really what is multiple chemical sensitivity and TILT. We're gonna talk about some of the misconceptions surrounding it. We're gonna talk about the challenges and getting diagnosed and some of those strategies that people can do to make life more manageable. So let's kind of orient everyone, though, to the conversation, if maybe they're not familiar. So can you give us a brief overview of what is multiple chemical sensitivity and TILT and why do they develop? What does it look like when it affects people?

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Aaron Goodman

02:50

Yeah, well, thank you again for having me. And you know, I should just preface our conversation by saying that I'm not a I'm not a scientist, so my backgrounds in journalism, and I used to make I still do that. I used to make documentary films, and I started this podcast. We're coming up to three year anniversary of The Chemical Sensitivity Podcast, so I think it probably best serve listeners if I point them to research or where I'm when I'm not sure I'll just say it. So what is chemical sensitivity? There are researchers, you know, physicians, environmental physicians, environmental researchers in health, who could provide a better answer. But what I can say, and I'd be happy to talk about my personal experience, you know? So I'm not, I'm not on my

Kendra Seymour

03:41

Do you want your personal experience? We can start there.

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Aaron Goodman

03:44

Yeah, I'll do, I think I'll do that. I that's maybe a good way to ground this conversation and just to share from my own experience. And on that note, I'm not at my best today, because, you know, living with this condition means, you know, every day is is an unknown, like I try to control my environment, you know, my home, my home is, is really safe, you know, but the moment I walk out the door, I'm often exposed to chemicals in the air that I that I inhale, that make me really ill. and sometimes I bring them into my home by accident. We have two my wife and I have two young kids, and they come home from school often. And because of the fragrances in the school, the cleaning chemicals, and often, it's really one of my major kryptonites. And I think this is, I know this is, the fact for a lot of people, is, is laundry detergent and fabric softeners. And we hear that in Japan, for example. You know, countless people are developing really severe chemical intolerance from what are called micro capsules. And these are highly potent laundry softening products. I believe that they're designed so the smell is, is really powerful, and it doesn't go away, and it fills neighborhoods, and people are becoming, you know, it's really difficult to protect their homes from this. In my case, dryer sheets are a real big challenge. It's one of my major kryptonites. So I take our dog out to for a walk. You know, five or six times a day, at least, my kids and you know, my my life, I'm in and out of the house a lot, and it just depends on who's doing laundry on that particular day. But yesterday night, my kids and I do Judo. And I'm not like a guru, Master, Judo master or anything, because the moment you say you do Judo people, I just want to be clear, but it's sort of a fun thing. My kids are really into it. I'm a novice, but I enjoy it, but it's been a challenge being in a Judo studio where, again, it's cleaning products a lot, that are a trigger for me, and the sense, the chemical sense, in talk, in toxic, toxic cleaning products, most of the stuff that people buy off the shelf. A lot of people don't know that these are really harmful for for not just people with chemical sensitivity. They're harmful for everyone. It's just that we react to them in the moment or shortly after. So yeah, the point that I want trying to make is my daughter, who's turning eight, forgot her the top of her Judo Gi, her Judo uniform. And so we I asked the Sensei, the teacher, if we could borrow one, and she had a blue bottom and a white top. But that's not the point. The point is that I had a feeling, because it's happened before, that there would be really powerful, strongly scented laundry products embedded in the fabric. And it's true, because

what happened last night was I wanted to clean the the Gi, the Judo uniform before I return it to the to the club, to the Sensei, to the teacher, and I didn't actually pick up on and it's one of those things that often I can forget that I have the illness, because I can go for a couple weeks and just because of luck, don't run into anything. But I'm all I'm often. I'm always reminded that I do have it because I got close the Judo uniform, I put it in the dryer, and just by touching it and breathing in the scent that was coming off of it. My symptoms, you asked about symptoms. So everyone's symptoms are different. And the challenge of diagnosis is that multiple chemical sensitivity, chemical intolerance affects many different systems in the body, you know. So it's neurological, so it's rooted in the brain and the nervous system. So for me, it's as if someone I'm an educator as well, as you mentioned off the top. So it's like someone takes my mind is a whiteboard, and someone takes one of those erasers and wipes it clean. So I can go from being perfectly alert and, you know, able to quick, think quickly and multitask to being having trouble putting my words together, and I'm having a bit of that trouble today. Have a bit of a quite a dry mouth and a dry throat. My tongue gets really swollen in and in leading up to our conversation, Kendra last night, I was really trying to be clear on what happens to me, and I was feeling in my in my mind, like in the center of my brain. It's like people talk about inflammation, and I could sense an inflammation that sort of creates brain fog. A lot of people have what's what we call brain fog, what's known as brain fog. So it's, again, I'm, you know, I'm, I have a PhD, I teach. I have kids. You know, my life is very active, and I can go from being really able to handle that really well to just being extreme fatique sets in, difficulty concentrating, parched mouth and irritable. Not so much these days, but in the past, I could get very agitated. Yeah, so that's and it generally lasts for me about 24 hours. There are some supplements that I can take. One is a mixture of magnesium and vitamin C and calcium that kind of reduces the symptoms for me. But there isn't a cure. There isn't a known cure for this condition. And so we just mostly in talking with folks, is we, we, someone said it really, really great we survive, and we try to survive. You know? We just do our best to survive, and one of the challenges is that it's it's not recognized by most physicians, and it's often misdiagnosed. We're often told it's in our heads, and we're often, you know, we're often judged by our families and friends and loved ones too. So it's not only that we live with a chronic, invisible, often invisible illness, it's that we are very isolated and often I'll come to an end of this really long thread and invite you to ask me more, but we're often unable to go to work and school, and often accommodations are not provided, because in order to get accommodations, one needs medical diagnosis right, usually and fortunately in my case, when I first developed MCS, I had the good fortune of having access to a physician who understands MCS and diagnose me at that time, and then I was able to take that diagnosis to other physicians. Some have told me to frankly, I'm quoting, get out of my office and don't show me that. And others have been receptive. And I think I'm fortunate where I am now, although in Canada are only two environmental health clinics, and

it's very hard to get in, and one in Vancouver doesn't even talk about MCS, so it's virtually impossible, and we know I over 50% I believe, of Canadians can't get access to a doctor, so we rely on medical clinics, walk in clinics. So to go to a walk in clinic and ask for a diagnosis, to get medical accommodation, it's really out of reach for for most people, and of course, in the States and in other countries, it's prohibitively costly, and the doctors just don't recognize it

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Kendra Seymour

12:06

There are so many threads there, Aaron, I think we're going to pull a bunch of those apart for listeners, because you really summed up so many challenges that come with this condition, and it's not all that unsimilar to those who've maybe been diagnosed with a mold related illness. There's a lot of overlap, and someone with mold related illness can develop multiple chemical sensitivity. We can maybe get into a little bit of that too. But let's start with the what you said. I think it's really interesting that you know, symptoms look different in different people, the initial trigger can look different for different people. Yeah, do you know what your tree was there? Like a moment, yeah, where things started to change, yeah,

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Aaron Goodman

12:45

Yeah. I'm really glad you mentioned mold, and I'm sorry for stepping on your toes there. It's just, it's a really good prompt, because researchers have shown that there are numerous triggers. And one of the theories that makes sense to me is, is also known as a rain barrel theory, right? And I believe this is the toxic and induced loss of tolerance or TILT. Not really a mouthful, right? But it makes sense, right? What induces, what causes this illness to come about? It's either a one time exposure to chemicals, toxicants, or it's a prolonged series of exposures at similar levels. And this research is from Dr Claudia Miller and colleagues in San Antonio University of Texas. So I encourage listeners to look for Claudia Miller's research, which has really been helpful for me and many others in understanding this illness. And Dr Miller and colleagues talk about a number of sub populations who have developed this illness after exposures to chemicals, and they include people who were present in New York and survived the events of September 11. Pilots who are regularly exposed to chemicals in fuel, people with breast implants, people who've been exposed to pesticide. Mold is also another trigger, and there are others. And so what's helpful about that research is that it clearly shows a correlation between exposure to toxicants and development of this illness. It's not that we just decide one day, oh yeah, I'm not feeling well. It must be, you

know, the thing I'm using, the product I'm using to clean my windows. No, it's that prior to that, you know, people with MCS have had a series of exposures to chemicals or one time. So from in my case, I believe I also have seen research that points to a genetic factor. So I also believe in my case, it was genetic and a lot of people report that too. And as you said off the top of our conversation, Dr Miller and colleagues, research shows that I believe 17 to 27% of the population in the United States reports some degree of chemical intolerance. Not everyone is debilitated. Not everyone has it at a severe level. But there is a range. There's a range, and I believe that, well, in Canada, over 1 million people have been officially diagnosed with MCS. And that's a lot, because the population is around 40 million. And again, as we were we were talking about, most people can't access doctors, so the fact that a million people have been diagnosed, and you know, when talking with researchers through The Chemical Sensitivity Podcast, it's been disturbing to hear experts in toxicology and environmental health say that it will be become much more prevalent going forward, because there's a severe problem with the regulation right. There are thousands of chemicals that we don't know how they what they do to the body, what they do to the environment, and particularly how they interact with each other, and that's really unknown. And just speaking of researchers, there's, you know, what I've learned is that illness used to be it's a new paradigm of illness, right? So these are it's a different kind of illness. I just talked with a researcher whose theory is that chemical exposures, pesticides and other are the number one cause of Parkinson's disease. And Parkinson's disease, the rates of people developing Parkinson's are spiraling, particularly in countries with lax regulation to chemicals, including China, which I had never heard of. So it's a new kinds of illnesses that are going to be really serious going forward. But going back to your question about for me, so I believe I had it MCS, chemical tolerance, TILT as a child, my parents smoked in the house. They used chemical products to clean the home that a lot of people used at the time, which were clearly not regulated well enough. And to this day, chemical products are in cleaning products and laundry are not regulated properly and enough, and I had a lot of ear infections. So I was being prescribed antibiotics a lot as a young person, and you know them, and and, and then in my youth, I had a prescription medication. And I believe when I look back, it was kind of a before and after scenario where I don't think I was the same after taking that prescription medication, and I have other symptoms, for example, a tennis elbow that was that I connected that medication, but also chemical intolerance. And then if we fast forward to about 15, 16, 17, years, ish years, ago, I was working as a journalist and teaching at a university in Bangkok for three years, and most people have no problem with this, but there's a termite issue in in Bangkok, and in much of you know, climates that are warm and termites do a lot of damage to buildings. So I think weekly, or every other week, a chemical pesticide company would come in, and they had big metal containers and they would manually pump pesticide called cypermethrin into my unit and in the hallways, and there

was a swimming pool outside, and I was I was often not home when they were there, and I didn't know, because I was renting and it wasn't my country, so I didn't really know what was going On. Didn't know it was being treated with pesticide regularly, but I would come back home after being at work for the day and become really agitated, really agitated, and I would develop the same symptoms that I shared with you earlier, brain fog, inflammation to the brain, you know, really thirsty and and then, and then, really fatigued, extreme fatigue, and just unable to function. And so that was a tipping point, another that was really a straw that broke the camel's back. After that point, I couldn't go outside without breathing, there's a lot of construction fumes there, and, you know, glues and paints and open air, barbecues, you know, and fragrances, cleaning products and fragrances that people wear on the body. When I mention it, I can even recall distinct smell being in the classroom and students wearing really strong perfume and fragrances that I really made it very difficult to be in the class because I was reacting basically all the time. All the time. I had very little reprieve from chemical exposure, so I was ill most of the time. And I had to, I had to leave Thailand, I had to to come back to Canada to be in a relatively cleaner environment, and over time, I've learned to to deal with it. And you know, one of the first things people do is look in their own home. Okay, what can I get rid of? What can I use? What can I stop using to make sure that my home is safe and I'm not contaminating my own environment to make myself ill. And then I think just being in my own home over time has allowed me to have less and less exposures. So I'm not chronically ill, but I do I'm still really, really sensitive when I go out, yeah? And when things come into the home, like the Judo uniform.

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Kendra Seymour

21:01

Yeah, I think you bring up so many important points, and I'll just speak to a couple of them before we move on. But you know, there's only so much you can control, like in your home, and then when you go out into the real world, people, most of us, have the luxury. We don't have to think about walking into the grocery store and the chemicals that were used to clean the floor the person walking by with laundry detergent or perfume. And you know, if we focus in just on the home piece, you know, the average person spends more than 90% of their time indoors, most of that is at your home, but it's other places, like schools and work too, and we're not thinking about the home chemistry side of things. So I know, when I reached out to you, I said, you know, this year Change the Air Foundation, we're highlighting kind of the home chemistry side of things, VOCs and other hazardous indoor air pollutants. Because in our home, there is so much going on between the glues and adhesives and our flooring and our furniture, to what our appliances are putting off to the cleaning chemicals. And you know, most often, we do not understand how all of

these chemicals interact with one another, let alone how they interact and affect us individually. And so we'll have other episodes, depending on when this is released, with like Laura Obler, Adler, excuse me. Andy Pace, Arnold Mann and a number of other people who talk about this, this often overlooked thing, because we can't always see it, and, you know, oftentimes we can smell it, but not always, right? And to your point, it was funny, you know, you were talking about cleaning. And as a society, some of us, at least in the United States, associate clean with, like fresh mountain breeze or like lilacs. Like clean shouldn't have a smell like and I think that's a hard thing for people to to understand. They think, if I you know that I don't want to name a product, but if I can't have that lemony sun, how do I know it's clean? Well, you know it's clean when you actually smell nothing. So you'd also mentioned, and I want listeners to know, Dr Claudia Miller and others who are doing some amazing work. We're going to link to some of her resources. We're going to link to there's a paper I knew you share by Dr Masri and Dr Miller and others about it looked at patterns of exposures in global phenomenon, and it talked about things like you mentioned after 911 there was the famous EPA carpet case. We talked about that in the episode with Andy pace Gulf War Syndrome. And I think the reason why these, if you've you know, ever watched the news or read a paper, these make headlines. And I think it's because there's a large number of people, and there is a defining, you know, incident exposure, and then it makes headlines because it makes people sit up and go, huh? What happened there? And that's not to say, though, this is not happening in individual cases to people like you and others. Every day, teachers in buildings, workers in certain conditions, really, anyone, anywhere, depending on the situation. So we're going to link to some of those resources. But one of the things that I would love to to, and you alluded to some of them, is to talk about some of the misconceptions. Because some people will say, you know, and this, this really breaks my heart. Oh, you're just being difficult because you don't like my perfume. Like, you know. And they kind of think people are exaggerating or overreacting or being like melodramatic like, can you talk about some of the misconceptions that are out there people experiencing this?

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Aaron Goodman

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Sure. I mean, I think someone said it really well, a listener, someone listens to the podcast, The Chemical Sensitivity Podcast, you don't get it till you get it. And I think it's true with a lot of things like, I mean, I didn't know what arthritis felt like until I got minor arthritis in my knee, right? You know? So I understand that, and I don't expect people to fully understand it, but I think what we what I've seen, is that people are often attached to the scents that they wear. And you know, in even in my own marriage, you know it's there been my wife has been so generous and

doesn't use any scented products. But there was a time when we first met, when she, she did wear perfume. And, you know, we it was a, you know, not an easy process, or it was a fairly long and complex process, of of have, of of educating, and fortunately, my wife is trained as a scientist. So, you know, when people have access to the literature or can read a short paper, it doesn't have to be a scholarly article. You know, there are some, you know, summaries that the Hoffman Foundation, for example, and I should just, you know, state that the Marilyn Brachman Hoffman Foundation funds, this The Chemical Sensitivity Podcast, and they really gotten behind what we're trying to do, and I'm super reputive of their support. And so they publish a lot of material that's really accessible for for folks to understand. And so yeah, but people are attached to to the scents and the cleaning products and incense sticks and essential oils and the whole thing. So what can we do? What can what can we do? We it's difficult to ask. It's difficult to ask. And I think asking can sometimes complicate things. It's not easy. For example, we live in a condominium, and dryer sheets, as I mentioned, are pretty big problem for me. Make me very ill. And, you know, a while back, I decided, well, what do I have to live like this? Like, what if people in this particular community could, would they be willing to take a moment and reflect on the impact they're having on me? Because they probably don't want to harm me, you know, if they knew? So I put up a flyer that just said, you know, there was a healthy option, wool dryer balls. And I don't, I didn't make it personal, but I said, you know, would you be willing to consider and someone, you know, tore them down, and someone contacted the strata and threatened to sue me, you know. So it's, you know, and we hear these kinds of over the top reactions a lot, you know, if people are using chemicals in their homes and neighbors asking politely, the reactions can be really aggressive and over the top and violent sometimes. So yeah, I think there's a sense of entitlement, unfortunately that people have, and it's really unfortunate because we share public spaces, and it would be nice if people cared for each other, and just recognize that it is a health issue. And we're not exaggerating, you know, it's, it's a debilitating condition for a lot, for a lot of people, it's not just that we don't like the scent of your perfume. It's really it excludes people. It excludes people. And, yeah, do we want to be discriminating against people and behaving in ways that force people to be on the sidelines of society?

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Kendra Seymour

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Yeah, I mean, this isn't just a personal preference thing, and it's much more than even just an allergy, it really has a physiological effect on the body. And, you know, depending on who you talk to, I know you've talked to people on your podcast, and the symptoms really very wildly. I mean, some people even end up resorting to they can't live in a condo or a traditional home or

community. Because, you know, if you think about everywhere you go, from the moment you wake up to the moment you put your head on the pillow, you know, out to walk your dog, to get the mail, to get in the car, to drive on the highway, to go to work, to then stop and pick yourself up lunch, you know, then you get your kids from school, and then you have to go to the grocery store, and then you have to go to sports practice, like there are so many interactions in a day that that they you know, the life ends up being living in not just isolation from people, but in areas that are more remote, you know, because I, yeah, I walk outside my house to walk my dog, and I'm like, somebody's doing laundry. I can smell it. Don't know who, because the houses are close together, but

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Aaron Goodman

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That's right, it's hard that can fill up an entire block. It can fill up an entire city block. So, yeah, you're to your point. You know, a lot of people do end up being unable to to go to school and work and do move, either living in vehicles, just out of desperation, you know, just like reaching a point where, like, if I was this, as Ill as I am, in this moment every day, because something in my home, and as you mentioned, oftentimes, it is our home, you know, and it's very if we're renting, for example, it's really difficult, because we have no control over what is in the home, right, whether it's been newly renovated with floors that are off gassing or fresh paint or appliances or contaminated air coming into the apartment, for example. So it's really difficult for a lot of people to have a safe home, and yet, a lot of people do resort to leaving urban environments, going into rural environments, in vehicles. I've talked to people on The Chemical Sensitivity Podcast who've done that women who lived in vehicles for years. It's really, really challenging. I know again, I talked about in Japan, I talked with a woman who lived in her vehicle for five years because of the laundry products. She had nowhere else to go. She had to flee, and her family didn't believe her. Her boyfriend rejected her, and then finally, her family decided to to turn a corner and took her, decided to open their home to her. But yeah, a lot of people, I know a woman who lives in New Hampshire in, you know, the winters are really, really hard. There's a lot of snow. She lives in an old RV because her body cannot be anywhere near people. And this the, the sacrifices that she has to find a way to survive.

Kendra Seymour

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Yeah, no one would choose this, right? Like, like, and I think that's what I wish people would understand who are kind of skeptical about this condition, I think too, like, you know, let's touch for a moment, because I know we're getting low on time. You know, we talked about the varying symptoms, we talked about the varying triggers, and then your initial trigger, you may then react to other things beyond what what initially triggered them. So why we're not going to, you know, you're not a doctor, and we're going to have an episode with Dr.Nasri and Dr.Dempsey on diagnosing and stuff like that, for people to listen to. So head on over to ChangetheAirFoundation.org, sign up for our newsletter so you can get notified when those are out. But can you talk to us just briefly what you've seen, like, the challenges with getting diagnosed, like are the criteria and things like that. Can you just highlight that for us?

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Aaron Goodman

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Yeah, I mean, one of the positive is, positives is that Dr.Miller and colleague have created a questionnaire that people can bring and it's called QEESI, and it's available on the Hoffman website. And if you just look for diagnosis, self diagnosis test for MCS, you can find it, and it's something you can do on your own and then take to a physician. And, you know, they may or may not be open to it, you know, yeah, but it is very hard to get a diagnosis. I think the majority of people with MCS do not have an official diagnosis. And, you know, some people suggest using different kinds of language, and I've started to do to do that. You know, instead of talking about reacting to fragrances, or if I ever do, I always remind my the doctor, who I, the GP, who I have good fortune to be able to visit, that it was caused by an exposure to pesticide. So I had a pesticide reaction. Just to implant that in his brain to remind him that I'm not making this up. I'm not just super fragile. This was a chemical injury. That's another term that people use. Mm, hmm. One of the challenges, yeah, and one, I mean, I don't have the right a complete recipe or solution, but one of the challenges is, because it affects many parts of the body. You know, I've gone into doctor and they just don't have time, you know, they have made up three, maybe two minutes. And if we have respiratory, neurological, cognitive, you know, my symptoms again, are they tingling in my spine, neuropathy was tingling in my legs and feet and ankles, insomnia, part throat, brain fog, like it's just too much for them to deal with in a two minute session.

Kendra Seymour

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Let me step in there. They're going to be like, we're going to send you to a neurologist, and we're going to send you to someone for your, you know, GI issues, and we're sending you to someone for your skin issues, and no one is connecting the dots that this is all connected you're seeing, you know, three, four, five, six, different specialists who are, this is a singular focus. Yeah,

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Aaron Goodman

34:51

Exactly. And that's in my case, that's what happened some time ago. And, you know, I went to a, was sent to a neurologist, and then they poke and prod. You with and like, No, you don't have a nerve issue. Well, of course, I don't have a neurological issue in that moment because I'm not reacting to a chemical. So I think functional medicine is the kind of medicine that looks at the connections and the root problem, right? As opposed to the western model of medicine that's most common, whereas you say we're looking at symptoms, you know, on its own, no, I don't have a dry throat problem or a swollen tongue problem, right? So it's very challenging.

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Kendra Seymour

35:33

You don't need an ENT right?

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Aaron Goodman

35:34

No I don't need an ENT

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Kendra Seymour

35:35

Oh, we'll send you to an ENT, so what we're going to do here for listeners is, we'll link to the Hoffman Center and the QEESI so that people can find that easily. You don't have to hunt. But are there, like, two or three strategies that have worked really well for you in terms of, like, how you navigate, living with this condition, that you can kind of leave listeners with?

AG

Aaron Goodman

36:00

Well, one thing is, you know, if you have to go out. And of course, you know, I do go out outside of my home. I carry a mask. I used to wear a really big mask, and fortunately, I found another mask that is more discreet. And COVID helped, although masks, because we know we can really politicize, but it's sort of, it's not 100% protection against chemicals in the environment. You know, scents in the air, but it helps a little bit. If I'm ever stuck in an elevator, or if there's dryer sheets while I'm walking around, I can just hold that up to my face. I don't need to wear it all the time. The other thing survival strategies, yeah, I think the the one of the big things is just sometimes we can, I, you know, I spoke with a young man named Daniel, who he is a he identifies as a universal reactor, like He's so sensitive to chemicals, he's he's one of the people who've had to live in his vehicle and flee cities. And he says like he can sometimes hardly believe that it's real, because it's just like, how could this be real? But it is. It is. So I think it takes a lot of inner strength to say, yeah, I'm really sick right now. I'm really ill. I'm going to give myself however long I need to just move slowly, move slower through the world, do less, and it will pass. And then I will get ill again. I don't know when, but I'll make it through that, you know. But today I'm not at my best, so I'll survive. And then maybe thirdly, you know, if I think one of the things, as you mentioned Kendra, is I had never spoken with someone with MCS when I first got ill, I found one person in Toronto who'd had it, who has it, and she held my hand and said, you know, it is real. This is what you need to do, and you'll be okay. You'll find a way. So I think connecting with others is really helpful. Fortunately, social media is allows us to do that, there's some excellent Facebook groups where people they're moderated really well, and they're full of great information. So even if we can't get a diagnosis at a physician, we can, we can talk to people who have this illness, who can validate it for us. And that's one of the goals of the podcast, is to help people connect with each other, to help people tell their stories, just sharing your story like you've given me an opportunity today is so rewarding, and it's really rare to have someone take interest and be caring. You know, it's surprising. You know, the number of people, has anyone in my life really stopped and said, you know, what's it like for you? No, no, I don't think it's happened, you know, except that we get each other people with this illness, we understand each other, and we're there for each other. We are. So that's one of the beautiful things about it.

Kendra Seymour

39:13

I'm so glad you brought that up, because that community is so important, and I'm so grateful that you offer that community through The Chemical Sensitivity Podcast, which we are going to link to in the show notes. So I encourage people to check that out, because, I mean, you've been doing that podcast for years, so there's a lot of great material there, everything from doctors and researchers to people living with it, and great tips. So I think it's a wonderful resource that you've provided for people because it is it is isolating, and whether it's multiple chemical sensitivity or Lyme disease or mold related illness or some other condition that's just poorly understood, know that you're not alone. Give yourself some grace. You know, as you go through this journey and don't give up hope because you can get through this, and there are ways that you can, you know, learn to live a new normal and find joy again. And it's so important for people to do that. So we're going to link to your podcast. But is there, is there? Are there any other resources you didn't mention that you'd want to point people towards, if they're looking into this, that you have found helpful?

AG

Aaron Goodman

40:18

No, I think, I think you've covered it really nicely. So okay, thank you.

KS

Kendra Seymour

40:22

All right. Well, Erin, thank you so much for your time today and for everything that you're doing for the community. I really appreciate it.

AG

Aaron Goodman

40:30

Thank you so much. Kendra, thanks for everything

Kendra Seymour 40:32

And for everyone listening. If you found this information helpful, if you'd like to learn more, do me a favor head on over to ChangetheAirFoundation.org, and sign up for our newsletter because it really is the best way to get great information like this directly to your inbox. We'll see you next time. Thanks so much.