Lyme And Mast Cell Activation Syndrome (MCAS): What You Need To Know Transcript

(Transcripts are generated by AI and may contain errors)

Introduction to MCAS and Lyme

Hi and welcome to another episode of the Healing Lyme Summit. I'm your host, Doctor Myriah Hinchey, and today we're going to talk about mast cell activation syndrome in relation to Lyme disease and other vector borne illnesses.

So Lyme is an inflammatory immune dis regulating infection that infects and affects every cell in the body. So it's not surprising that it's going to cause dysfunction in mast cells in a lot of patients to mast cell activation syndrome causes a ton of different symptoms, and they can affect every single system of the body, just like Lyme and vector borne diseases.

And there's quite a bit of overlap in the symptoms. So here to talk us through, teach us more about what it is, what the relationship is and what to do about it is Tanya Dempsey, MD.

So Doctor Dempsey is a board certified internist and she is an expert in chronic disease, autoimmune disease, as well as mast cell activation syndrome.

So welcome, Doctor Dempsey, thank you so much for joining us. Let our audience know how you came to specialize in this. Well, first off, thank you for having me.

One of my passions is educating. And so I love talking about what I what I do every day. And that is take care of patients with complex chronic diseases.

How I landed on mast cell activation syndrome is a little bit of an interesting story, but the reality is that I've always been very sort of open and always with this mindset of root cause medicine.

Even when I was doing general internal medicine, I always wanted to understand why something was happening to a particular patient. And I because I was interested in root cause stuff.

I also was always talking to patients and listening and more importantly, listening to them. And and so when you listen, you're more likely to find things and start to understand how the pieces fit together.

How Tanya Dempsey Entered the Field

And so once I so I so actually looking back, the point is that I think I was seeing a lot of patients with mast cell activation syndrome. And now I can see that in retrospect.

And I knew that there was something immune dysregulated, but I didn't really understand the full aspect of it until I was already on my own, in my own personalized medicine practice where I, had that one patient that was not getting better and was getting worse and had multi-system symptoms that didn't really fit into any other box that we could find, that there was nothing else that really explained her symptoms.

And, and I remember one day, doing a little literature search, I was on Pub Med, I think I was even on Google, because I was really determined to figure this out.

And I came across mass activation syndrome, and this was probably somewhere around 2014, maybe close to 2015. And that was really just kind of the beginning of, of the information we had on, on me.

But once I sort of looked at it, looked at it and thought about and talked to the patient about it, it all made sense.

And then I connected with doctor, Larry Afrin, who is really considered I consider him the world's expert in mass hydration syndrome.

And, and then eventually I brought him on board to my practice. And so we're practicing together and researching and studying and really trying to understand this disease better so that we can help more patients.

So that's amazing. That's that's great. What better than to bring in the world expert right to your practice and work with him? I love that. Thank you for everything that you do.

So let's start by talking about what is mast cell activation syndrome for the listeners. You know, who are patients. Sure. So you know, the I think the best way to think about it, you know, we the the quick version of it, the elevator speech on it really is it's a chronic, complex multi-system disorder.

And so what that really means is that this is a condition that affects multiple parts of the body. So symptoms in one part of the body alone probably is not Marcel activation syndrome.

And we're looking at mast cells in particular. Right. So let's talk a little bit to understand this syndrome. I think it's good to really even understand the cells involved in the syndrome.

And these cells, these mast cells or white blood cells. Now we have white blood cells, lots of different ones. They they fight infection. They help protect us from the environment.

They do a lot of different things. Now. Cells are white blood cells that actually live in tissue in the body. So we have white blood cells that are flowing through the blood vessels.

They're in your veins or in your arteries or they're circulating. Now cells actually stay in in tissue in the organs. And that's where they are. Our first line of defense against everything the external environment, the internal environment.

And they are part of what we call the primitive immune system or the innate immune system. So they are positioned to be the first line of defense. And one of the ways they protect us is that they when they see something they don't like, they literally explode.

We call it granulated. They release granules of chemicals. We call those mediators in order to fight off what they see as foreign. Now mast cells are involved in allergy.

So I'll give you a little bit of a primer on allergy. So if somebody has just allergies they may or may not have mast cell activation central. But they're let's say allergic to pollen.

The mast cells in the respiratory tract see the pollen. They see that there. They're allergic to the pollen. They tell the mast cell that there's a signal to the mast cells that that the the pollen is bad.

What Mast Cell Activation Syndrome Is

And they need to be it needs to be dealt with. And the way that the mast cells deal with it is they'll explode to release histamine. That's one of the one of the drivers of allergic symptoms.

Histamine is very inflammatory. So in response to this the histamine you get everything swells up. You might get itchy, you might have trouble breathing.

There are lots of different things that happen. Right. That's what mast cells are responsible for again towards this allergy. Now in an allergy situation typically you kind of sort of deal with the allergy.

You avoid the allergy, you get allergy shots, you take allergy medicine. And if it's always you're not exposed to what you're allergic to, generally speaking, those mast cells will sort of just hang out and wait for the next thing in nasal

activation syndrome, which, by the way, could include allergy but doesn't have to include allergy.

You can have nasal activation syndrome without allergy, you can have allergy without nasal activation syndrome. And you can have allergen mast cell activation syndrome.

But in people with this nasal activation syndrome, what happens is these mast cells, which I which I said are really all over the body. I talked about allergy in the respiratory tract and in the skin, but in mast cells are everywhere.

When they are read a signal that's abnormal to it, they will explode. They will release various chemicals. Histamine is just one chemical that they can release.

They don't have to release histamine. Many mast cells don't make histamine. They make other chemicals or over a thousand different chemicals that mast cells can produce.

And and in in these in the in this release of these chemicals, these chemicals then are sure they're sort of designed to maybe help kill whatever they're trying to trying to kill.

But but really it backfires and all that. Those chemicals are in our tissue and it causes inflammation. So so again so mast cell activation syndrome. These are mast cells that are abnormal.

They're reacting abnormally to the environment. They're maybe triggers that are real but they're probably not that bad. Somebody without cell activation syndrome may or may not even realize that there's something bad in the environment.

But people with and cars are reading things at a very, very like low level. So they're more it's more intense. It's more, more aberrant, more abnormal.

And, and that leads to a variety of symptoms. And it can affect every single body part organ system in the body to to meet the criteria for mass activation syndrome, you typically need more than two systems involved.

So again, if you only have allergy and you only have respiratory symptoms with the allergy, but you have no other problem in any other part of the body, that's not nasal activation syndrome.

If you have allergic symptoms, let's say and you have symptoms that involve let's say you have, bowel issues, gastrointestinal issues, if you have, heart issues or palpitations, maybe you have neurologic symptoms, neuropathies.

If you have things that are involved in other parts of the body, then you can say this is a multi-system condition and that may meet the criteria for meso activation syndrome.

But I want to make a point about allergy and histamine. And that is that again you can have allergy and mast cell activation syndrome. And you can have nasal activation syndrome that looks like allergy but is not truly allergy.

So some of my patients wind up in an allergist office and they know their, let's say, reacting to pollen, or they're reacting to a food. They get tested and everything is negative.

It's not that they don't have allergy, but they have have a exaggerated response from the mast cell through a different pathway. So it looks like allergy, but it won't meet the criteria for a true allergy.

But there are also mast cell patients who have no allergic symptoms whatsoever. And this is probably the most misunderstood piece. And I really want to drive this point home because a lot of patients are discounted when they say they don't have allergic symptoms.

I think that since this disease and this the syndrome is being popularized, I think there are more and more practitioners who are starting to understand it to some extent, or at least they've heard it, but they make an

assumption that there has to be people have to have allergic symptoms, they have to have trouble breathing, or they have to have respiratory symptoms of various kinds or hives.

But there's a subset of patients with mxs who do not have anything that even resembles allergy. And they still have mast cell activation syndrome. So if I can send this message home to to patients, to maybe their practitioners listening, if the patient has multiple symptoms in other parts of the body, but they don't have allergy, they can still have mast cell activation syndrome.

Okay. That's so. And and we need to have at least two systems being affected. Correct. So two questions. The first one is what are the common like. Obviously we're talking about infections inducing this.

So in addition to infections what are some other things that would cause someone to develop mast cell activation syndrome. What we understand is that there's the vast majority of people with mast cell activation syndrome are probably born with a predisposition they're born with, we'll call it somewhat dysfunctional mast cells.

Maybe there's a familial history, maybe there's there usually is other family members who have some flavor of mast cell activation syndrome. They so they're born with with this predisposition.

And we call this idiopathic really nasal activation syndrome. So it starts at a very young age. And then they have the predisposition. It doesn't mean they're going to go on and developed full blown MERS.

But they might have mast cells are a little bit more finicky. And so over time with various insults, various exposures, those dysfunctional mast cells become can become more dysfunctional and then over time lead to the full blown development of nasal activation syndrome.

So there are patients with Lyme disease with infection who had muscle activation syndrome before the infection, but maybe they had very mild symptoms.

And then they get the infection. And it could be Lyme, it could be Bartonella. The BCR, it could be a parasite, it could be a virus, could be the flu, could be Covid, could be Epstein-Barr, could be could be even a toxin in the environment, a pesticide, a mold toxin.

There are lots and lots and lots of things in the environment that can trigger the mast cell. And with every trigger of something sort of dangerous, foreign, toxic, these now so sort of basically reach a new sort of baseline where they're more reactive and more reactive and more reactive over time. Right.

So, so I would say that that is definitely the majority of patients, at least that I see in my practice. When you take a really good history, sometimes patients think that a particular incident is what caused their mass activation syndrome.

We see this a lot actually in the long Covid world, very healthy people who then got Covid and then have lingering symptoms. But really the majority of them, I would say, and I would never say all of them, but the majority of them had some flavor, probably of em.

Causes, Triggers, and Diagnosis

CAS when we take a good history, we see that they were some things already, sort of at a very low level. But these are very healthy people, so it's not really affecting them.

But then that major trigger brought it out there. There are there is a subset of patients, though, who have what's called secondary mass isolation syndrome.

And they have, they have, let's just say totally normal mast cells. There's no genetic predisposition, there's no family history. There's no nothing. They they're born normal, normal history.

But then at some point in their life, there's a trauma, an infection, a toxin exposure that then literally mutates these mast cells to become dysfunctional.

But in that case of secondary, the taking away the trigger may actually reset the mast cells back to completely normal. Someone who was normal lived in a moldy home, got nasal activation syndrome, got mold exposure, and mold mycotoxins, illness.

And then they're treated. They leave the house, they get treated for them. If they didn't have anything wrong before, it's possible that their mast cells will reset and their health will just go back to where they were before.

I would say that's actually, unfortunately, rather rare because most of those patients with secondary, they, those mast cells get mutated in a way that they may not return to normal.

And then that does suggest that maybe there was something going on earlier that we just didn't even realize. So it's complicated, but that's sort of the way I think about this.

Okay. So is it a clinical diagnosis or are there tests that you can do to diagnose that, or is it a combination of the two? Yeah, I think I think the best way to think about it is that it really should be a combination.

You need the clinical symptoms, you need the clinical sort of manifestations. You need to be able to understand. Right. The patient has to meet that those criteria of multisystem, the disease that doesn't or let's say symptoms that are not explained by other diseases.

But sure, I you know, I'm a scientist at heart. And so I really would like to have a diagnosis. I think that getting a diagnosis using testing gives the patient, validates the patient, gives them a credible diagnosis that that they can then tell their other providers about that again.

And they have that credibility that they're again, they're not discounted. They're not disbelieved. Right. So I think it's important the challenges a testing is can be difficult.

And so so I think there are there's always going to be people who are not going to be able to either do the testing or they do the testing, but the testing doesn't show any anything abnormal.

And so we just have to be careful, like there are cases where we can't find the abnormal results. But really there's everything about their clinical picture, including response to treatment.

You know, they've tried things for mast cell activation syndrome and they seem to get better. So we make an assumption that they probably have it. The testing involves really a handful of tests that we can measure, mediators that we measure.

Actually, these are the things that mast cells release when we try to to grab them from the blood or in the urine. I said earlier that mast cells make over a thousand chemicals.

If we only have a couple a handful of things that we can measure at most, they're going to be people who don't meet the criteria by our testing. But that's because maybe they have one of these mediators that we just don't have the testing for.

So I think we have to, you know, we have to treat the patient ultimately. And the patient is the one that needs to be treated, not just the tests themselves.

Yeah, absolutely. Do you want to share with the listeners what like those, you know, handful of tests are because I know like testing for histamine is not you know like that's that's not it.

So what are the other mediators. I mean I know histamine plays its role, but as you've pointed out to me, histamine is not the end all be all. So what are the other things that we can look at and evaluate again with the clinical picture.

Yeah. So so we histamine a plasma histamine and a whole blood histamine might be worth doing because when you get it's it's helpful. It's one piece of information that you can be used towards making the diagnosis.

And ideally I would want to not only do I want to body parts affected essentially, but I want two pieces of laboratory evidence to support the diagnosis.

So histamine can certainly be a positive and that could be one point of reference. In addition, we have pomegranate a some of these mediators are not specific to the mast cell.

They have other cells that are are being made or making them I should say. But we can use some of these depending on the level components. One. Triptans is the one that that gets the most press.

Unfortunately, because phytase is made by mast cells, there are lots of people who do not have elevated teas. But some of the old thinking on this is that you need an elevated triptans to make the diagnosis, and you need to be testing when people are really symptomatic in order to see if the case goes up.

And I will just say that again, I think that's a different way of approaching us. And so our way of approaching it is saying, sure, if we get an elevated triptans, we're going to act on it, which we're going to try to figure out what that means.

But if it's negative, it doesn't mean the patient doesn't have a nasal condition. Elevated trip taste, though, can mean other things. And so that's going to require other types of testing.

But it rarely is a marker for mass activation syndrome alone. That's what I'll say about triptans. And then there are markers like heparin. Heparin is a really interesting chemical.

It is a blood thinner. It's used in hospitals when people have blood clots. The mast cell is the only cell in body that actually makes heparin and really, really minuscule amounts.

But if if we can, there are certain labs that can measure down to those minuscule amounts. And when we catch an elevated heparin, in the blood, then we know that it must be.

Now, cell activation syndrome is a very specific marker because and sensitive actually sensitive and specific marker because there's really nothing else that could be doing that unless somebody is actually taking heparin.

So that's a really great test. And then there are urine markers mediators that we can detect both in random urine samples and in 24 hour urine samples we have things like and methyl histamine which is a metabolite of histamine.

We have to go trains. We have prostaglandin D2 I get it two three dinner 11 beta prostate gland and F2 alpha. That is a mouthful. Yeah a little bit doctor.

After that that's so seamlessly. It's just so beautiful. But I, I usually stumble on it. But, in any case we have so we have these various mediators that we can collect in the urine.

The challenge is really that the people who are collecting at the labs that you're going to, they have to know how to handle the specimens at home. People have to be really careful with the specimens.

They have to keep it cold. And so there's a whole routine. Or we have a we don't do the testing in our lab per se, but we do have a lab here in the office where we process everything and then get it to the lab that's actually going to run the samples.

And we have a whole technique here, how we educate our patients and how we process things so that we we get hopefully more reliable results. Right. Wow. Okay.

So Doctor Dempsey, let our listeners know how and where they can contact you if they're interested in more

information or becoming a patient, and let them know if you have any upcoming events or exciting news to share.

Sure. So, you know, I'm on social media. Instagram is, dear Tanya Dempsey, M. D., Facebook Doctor Tanya Dempsey, my website doctor Tanya Mccolm. Lots of I've lots of information.

I do lots of videos and podcasts. I have a I have a new podcast. So I do put that on my social media. But if people want to listen, it's called mast Cell matters.

And and that's been exciting. We have a few more of a few already released, and we have a few more coming down, up, down the pike. But I think having this podcast about mast cell activation syndrome is really great and exciting and just want to keep getting the word out and interviewing some of the best of the best in this field.

And, I think that's all I can think of for now. I'm sure there's. Okay, great. I'm excited to hear your podcast. I definitely want to learn more. I know, like the tip of the iceberg here with mast cell activation syndrome.

So, Doctor Dempsey, I have so many more questions for you. We haven't even really talked now. We talked about how it's multi-system, but we haven't even really gotten into what the actual symptoms of mast cell activation are.

So can you share that with us? Sure. Well, I'll start from sort of head to toe. You know, I think that's probably the easiest way to do it. And again, there are some symptoms that can be linked to other conditions.

So just because you have the symptom doesn't mean you have mass or activation syndrome. We want to be clear right. Headaches are a are let's say a symptom of of and cast migraines can be actually a symptom related to cast people can have migraines and not have them cast.

Right. So I just want to be clear that would be careful not to attribute everything to and cast, but headaches definitely are. A possible symptom. We see eye issues, blurry vision, change in vision.

Testing and Biomarkers for MCAS

We see ringing in the ears, change in hearing, trouble swallowing. There's various digestive issues. Can be, slow motility issues, gastroparesis, colitis, respiratory issues can be like an asthma like situation.

Could be a cough, could be just reactivity in general to things in the environment. That way the skin, there could be hives, but there could be other kinds of skin manifestations.

Things that look like eczema are psoriasis, are lots of different things that may be linked to and from a manifest like and cast. There are, I think about like going down to the pelvic region.

In men we sometimes see pelvic pain. They can have testicular pain so they can have post orgasmic pain. Women too. They can have the same they can post orgasmic pain.

They can have pelvic pain. They can have endometriosis, various menstrual irregularities, various hormonal irregularities. And, I'm sure I'm gonna. I'm, forgetting.

But then osteoporosis is associated with MERS, arthritis, muscle issues, neuropathies, other neurologic issues, neuropsychiatric issues, depression, anxiety, OCD, eating disorders.

You know, again, the like the list goes on. I'm probably forgetting something in that makes, connective tissue issues, cranial cervical instability, tethered cord, a sleep apnea, the list goes on.

Okay. So how does a Lyme, in your opinion, like how does that infection induce mast cell activation syndrome. Is it infecting like is it infecting the mast cell.

Is it just a part of like the immune dysfunction. Is it the inflammation? Is it all of it. Like do we know what the actual

connection is that triggers this in some patients?

Because as you're, you know, rambling off the symptoms, it's like, yep, that's a symptom of Lyme, some Lyme some, you know, on and on and on. It's like, you know, there's just it's it's very close to being 100% overlap in the symptoms.

Oh, absolutely. Absolutely. So the way I look at it is that for some patients, the line is a trigger for their mast cells. So I said early on right that the mast cells are reading your environment.

We know that that as, as part of the primitive part of the immune system, the mast cells from the from, from, you know, thousands, tens of thousands of years ago, mast cells were helping us fight off parasites.

They were helping us fight off funguses and bacteria and lots of things. So if that's their job to help us fight that, those infections, you can imagine if you get a chronic infection like Lyme or potentially chronic infection like wine, that you're going to set off that part of the immune system and rev it up.

The problem is that in chronic type cases, the mast cells are then constantly seeing this infection and they're constantly reacting. So I think there are a couple of different things that happens.

The line kind of spurs on that. Those mast cells, the mast cells talk to other parts of the immune system. They talk to the part of the immune system that produces antibodies.

We have these, other white blood cells, lymphocytes that are involved in we have T cells and B cells. We have these cells that make antibodies. So line patients have positive and A's.

And when we type factors and they have, Hashimoto's and all of a sudden they have all these antibodies. And so what we believe is actually that the mast cell, the the responsible for sending the signal to these cells, like there's danger, we got to do something.

And that part of the immune system starts dysregulated, the starter starts making antibodies just trying to fight. Not very effectively unfortunately, but nonetheless trying to fight off infection.

So I think that's that's one part of this. I don't think that line is directly infecting mast cells, although I guess it's absolutely possible. We just haven't seen that yet.

You know, I think there's more research that needs to be done. And then I think the other parties that once you've had an infection like line. So for some patients, the immune dysregulation piece of it is more pronounced than the infection piece of it.

So even in some patients who are treated and may be treated effectively, maybe their immune system continues to fight. And there are others where I don't really think the infection is gone.

I think it and I think the immune system is dysregulated, but I also think the infection is still there, spurring us this on and keeping the mast cells continuously in a state of disarray, constantly releasing these chemicals, constantly causing inflammation.

And the way I think about it is I think the symptomatology okay. And this some of the stuff I'm saying we have not published on yet, okay. So but it needs to be published.

But what I believe is that the symptoms that patients are experiencing with, let's say, line or the BCR or Bartonella or whatever, the vector borne infections we're talking about, some of the symptoms are actually, I think, being driven by the mast cell and some of them are being driven by the actual organism.

I think it's a combination of both. And I think in some cases when you treat infection and you get what we sometimes call a time or reaction for some patients at halftime, a reaction is in fact mast cell activation syndrome.

It is the release of toxin, let's say, when you're treating those infections. But then that is flaring the mast cells even more, causing that whole set of symptoms that looks like it could be a worsening of their Lyme, but may in fact be part of the mast cell response.

Right. So and we know that so much of the works is is in inflammation driven too. So like this makes sense, right. That the mast cells actually playing a role like in reaction to the LPs maybe and causing part of that, this inflammatory piece of the Herkimer reaction.

That's very interesting. So what treatments and interventions and please talk about pharmaceutical as well as nutraceutical or herbal, whatever you would like to comment on, you know, do you like to use or are available to treat mast cell activation syndrome?

Well, first and foremost, the number one thing you need to do when we think about treatment is really to first make sure that you eliminate triggers. So if you know that you're exposed to mold, you know that there's something in your environment you're dealing with with a very stressful event.

Whatever it is, you've got to deal with those things first before even, you know, thinking about medication and all that. Those are going to be important.

But as long as you're constantly being exposed to the triggers, it's going to be hard to treat. And that includes the infection itself, right?

Symptoms Across the Body

And sometimes with some patients, we there's a little bit of a like I think I think of it like a seesaw type of thing going on between I'm trying to treat the line, but I know it.

If I don't treat the mast cell piece, they're going to flare more. But if I don't treat the line, the mast cell flares more. So he kind of you know, is a little bit of a catch 22 in some ways.

And so that's like the one part. And then to treat the mast cell directly, to treat to to basically calm this situation down. First line would be what we call antihistamines H1 walkers and H2 blockers.

So we said earlier histamine may not be the whole story. But having said that, mast cells typically do have that have histamine receptors on their surface, those receptors on their surface or what is what they are reading the environment with.

And so they have these histamine receptors. And even if histamine isn't a major issue or a major mediator, sometimes putting that H1 blocker, that histamine one receptor blocker, antihistamine can maybe send a signal to the mast cell like, hey, calm down, stop reacting so much.

For some people where histamine is an issue. Yeah, blocking histamine at the level of the mast cell, but also in other cells in the body can be helpful in reduced symptoms.

And there are lot of over-the-counter antihistamines and there are some prescription antihistamines. We have different histamine receptors all over our body.

So we're talking about these typical sort of antihistamines or what we call H1 blockers Claritin, XYZ, XR tech, Benadryl, things like that. And then we have these other antihistamines.

They're called H2 blockers because they block a different histamine receptor. The H2 is tend to be more in the GI tract. They are sort of elsewhere. But but a lot of them in the GI tract.

And so a lot of these drugs are used actually for GI symptoms for reflux and heartburn. But they can help block histamine things like Pepcid or famotidine, tagamet, Zantac.

So things like that. So having finding the right one of the H1, finding the right one for the H2 that's sometimes is really, really helpful. There are other medications that that we use.

There are massive stabilizers. Keycard often is one. Crumlin is another. Low dose. Naltrexone is one of my favorites though certainly doesn't work for everyone, but can help modulate the immune system beyond the mast cell from a from a supplement perspective.

From a like nutraceutical perspective, there are things that digest histamine down diamine oxidase. There are things that block histamine, vitamin C, and quercetin.

They also can be nasal stabilizers. There are a number of other sort of natural products. Resveratrol is another one. There are lots of them that actually have some mast cell stabilizing properties.

And then again, lots of other drugs potentially that can help. And all the way over to chemotherapy agents potentially. I have no idea that this is the problem.

What for each person is going to work for them? Which one is going to work best? That's some of the research actually, that we're trying to do is trying to look at the mast cells to see if we can do genetic sequencing, to figure out that this particular Marcel maybe is making more of, histamine.

So we know that we're going to use everything possible for histamine, but maybe that's the cell that's making more prostaglandin D2. So maybe we need to target things and use things like like Celebrex or Mobike or and salads.

So once we can get to the part of the research where we can really kind of determine what the person's main issue is, I think it's going to be much easier.

But right now is a lot of trial and error, right. So it sounds like there's kind of three goals. So number one is to block the two histamine receptors.

Number two would be to do things to stabilize the mast cell and make it a little bit more tolerant to the environment. So it doesn't granulation as easily.

And then number three would be to kind of like gobble up the histamine and the inflammatory compounds. So like you know maybe like proteolytic enzymes something like that.

But the big above all of that is finding what that trigger is, especially if it's an infection or a toxin or something that we need to actually focus on either getting out of the patient or getting the patient out of that environment.

Right. If it's an environmental trigger. Exactly. So awesome. Okay. So with any of these interventions that you've mentioned, are there side effects that people should be on the lookout for?

I think there are a couple of key points that I think we need just to talk about, in addition to all these big triggers that we talked about in the environment, medications and supplements are combined with excipients during the manufacturing process.

You know, you take, a Claritin. There are different formulations of Claritin. Some of them have lactose in them, some of them have mannitol, some of them have their various ingredients in different formulations.

And so for some patients they don't realize it, but they may be actually sensitive to one of these excipients. And that so they're not they may react to, let's say, to an intervention, it may not be the drug itself.

Lyme, Bartonella, and Mast Cell Dysfunction

It might very well be one of these fillers or it's at the ends. We see that in the pharmaceutical side, and we see that on the nutraceutical side. Magnesium story microcrystalline cellulose.

There are a number of things that are quite ubiquitous in in supplements, but that for some patients might be an issue and for others, not at all. So I think paying attention if you if you're if you're someone who trials lots of medications and supplements and reacts a lot, my guess is it's not you're not reacting to all those compounds.

You're you're probably reacting to something that's in the mixed with them. So I would go, you know, I have patients who create elaborate spreadsheets to try to figure out what the overlap between the different medications are, to try to figure out, oh, wait a second.

There's this one ingredient that's been in everything I've tried. Now, maybe that's why I'm reacting. So now either you have to find a formulation without that or you have to compound it.

So so it is it can be complicated but but definitely can be very much worthwhile. Because if you could figure that out, you then wind up having options and maybe being able to tolerate a lot more than you thought.

So that's the one thing that I would always keep in mind in general. You know, these drugs should either work beautifully, not work at all, or cause weird reactions.

And these reactions may be the exception, but it could be the compound, the drug, or the or the supplements. So again, working through all that I think is important and having somebody call, I feel bad because there are lots of patients out there who are trying to manage this on their own because they don't have providers, but I hope that the more we educate, the more providers there will be out there who can support patients.

It's much easier to do this, you know, it's much easier for me to work with my patients on this than for the patients to do this completely alone. But if you have to do it alone there, there are ways to do it, you know, and you just have to be rather methodical about it.

Yeah. Are there things from like a lifestyle perspective that patients can do to help to mitigate some of the symptoms? So yeah, that's a it's a good question and it depends I think it's important for for patients to try to find things that generally help their reactions acutely.

There may be things like some patients who know that dye free Benadryl liquid is a rescue for them, and they know that if they're having a reaction, they can turn to that.

So they react to, let's say they're trialing something else. You know, they can always turn to their rescue Benadryl if they, let's say, reacted to the Claritin that they took or something else.

So but some patients don't have that. Yes they are. They're still searching for the thing that's going to get them out of the flare. So there's no, you know, unfortunately, you know, there's no specific thing.

Everyone is different. Okay. So what would you say are your top three most important take home points for our listeners. So I think number one would be to, to always really believe yourself, always trust your own instincts.

And then if you feel like something is is not right and you're not getting answers to keep looking for someone who can help you with those answers. You know, I think that mix is just so complex and, and so many patients are really not, understood or are blamed for exaggerating or, or, you know, was a thought.

You know, I hate the word gaslighting, but in the sense that is what it is. And, I think that just to trust your instincts, you know, you know your body best.

If there's something not right, you, you know, fight for it. It's hard, but you've got to fight for it. You know, that's like, that's the number one thing.

And try to find people who will listen because there are more and more.

Treatment Approaches and Trigger Management

I mean, that's the thing that is reassuring to me, is that every day I connect with other practitioners who didn't know about it yesterday, but today heard about it from a patient and now wants to learn more.

Now they're going to help more and more patients. So I'm hopeful you know, that they're there. They're out there to help. I guess the other thing I would think about is that, you know, if your symptoms are, you know, a little more unusual, unique, again, don't fit into a box.

Keep, keep working to try to figure out what may be missing. I think there are lots of Marcel patients out there who actually don't know that they have Lyme disease, vector borne infections, mold toxicity.

So I'm going to say it like both ways are lying patients who don't realize have mass activation syndrome. And and vice versa. Right. So I really want to encourage people to to keep searching for the root cause.

There has to be an answer. There are. Absolutely. And test patients out there who don't have infection necessarily. I don't think there are a lot of them. That one.

I mean, that's a strong statement, but I don't think there are a lot that don't have something else that continues to drive and drive these these symptoms.

But again, in medicine, nothing is ever, all or nothing. Right. So, so I just think that keeping, aware of these things, asking to be tested, making sure that we're not missing something, at least in my practice, Bartonella is probably even more common than Lyme disease for lots of reasons.

And there's absolute overlap between the nasal symptoms and Bartonella. And more and more, we're seeing these patients who have done everything for their mucus and are not getting better.

And really the the reason is they're not responding because there's infection there that hasn't been addressed. So, and I, I agree with you, I think that that is, more often than not.

Yeah, I think so too.

Practical Tips, Takeaways, and Resources

Like sometimes I hope I have this sort of, not philosophy, but sort of way of thinking that I, I wish it was it. You know, I just wish that we could not have to worry about the infection piece of this, you know, it's, It's exhausting.

It's, it's life changing. It's, you know, and we're seeing so many young people afflicted with it. But the reality is, as much as I don't want that to be the case, the reality is, is the case.

And, and we have to search forward. And one of the things that I, that I really, really that gets under my skin the most is when people say, I was tested for Lyme and I don't have it.

Yeah, but they weren't tested for Bartonella and they weren't does it for Bbca, and they weren't tested for tickborne relapsing fever. They weren't tested for all these other things.

And so how do I know they don't really have one? So and they weren't even appropriately tested for Lyme. Yeah. Well that's a whole lot. Absolutely. Yeah.

So if someone needs more information, what resources are out there and available for them. And again, please share your information in case somebody would like to get a hold of you.

Yeah, I do a lot of writing. So I have I blog on my website Dr. Tonya dempsey.com. I do a lot of reels, videos, webinars, things like that. I post on my Instagram, which is Dr.

Tanya Dempsey and and then of course face book a Dr. Tanya Dempsey have or doctor Tony Dempsey I would

say. And so I, I just like to put out a lot of I do put out a lot of content.

And I'm always thinking about these questions. People post questions on my Instagram all the time or Facebook, and I try to address those with new reels because I'm constantly the patience the people out there who are listening or actually teaching me.

I'm not just teaching them, they're teaching me because the questions they bring up are so profound, so insightful, makes me think even more that I want to get out there and do the research and provide more information.

So I'm very interactive. I like that, I like to I need to continue to learn because I know that I, I know probably this much, even though I may seem like an expert.

Right. I know this like a tiny amount compared to what I think. Really, that we really need to know. Yeah, I think we all need to keep learning, keep searching, keep learning.

And, you know, our patients are our greatest teachers. I know I learned so much from my patients so much every day. Thank you so much for joining us. Thank you for sharing your expertise.

It's been amazing interviewing you. And thank you to all of our listeners at home. We will see you, on our next episode. So have a great day.