

Episode 1: Carly's Story

Narrator 00:00

Be inspired, supported, and empowered. This is the Global Healthy Living Foundation Podcast Network.

Carly 00:10

And sometimes what I find most interesting is as much as I'm an advocate, and as much as I'm knowledgeable about all of my illnesses, sometimes I find them making me look out for things that I hadn't even thought about.

Sarah Shaw 00:25

Welcome to The Asthma Podcast, a podcast that shares the real stories of people living with asthma. I'm Sarah Shaw, Senior Manager BIPOC Community Outreach at the Global Healthy Living Foundation. In this edition of The Asthma Podcast, we will dive into the stories of LGBTQ+ asthma patients within the theme of "Love Should Take Your Breath Away, Not Asthma," exploring how LGBTQ+ individuals navigate identities, relationships, and asthma all at the same time. By sharing these stories, we hope that you feel inspired, heard, and more empowered through you or your loved ones asthma care journey. As a member of the LGBTQ+ community, this topic is very important to me.

Why the focus on this community, you ask? Well, a 2018 report by the Human Rights Campaign Foundation found that 21% of the adult LGBTQ plus population in the United States had asthma, compared to 14% of the non LGBTQ plus adult population.

In today's episode, we'll hear from Carly, an asthma patient and the Chief Research and Innovation Officer and co-host of Lupus Chat. Carly's perspective as a person living with multiple conditions offers unique insight into her experiences living with asthma. Let's dive into her story.

Carly 01:47

Hi, everybody, I'm Carly. I live with asthma and other chronic illnesses. I am the Chief Research and Innovation Officer for Lupus Chat. I am also a member of the NIH's COVID-19 Treatment Guidelines Panel as well as a research lead and liaison with the COVID-19 Global Rheumatology Alliance.

Sarah Shaw 02:14

Hello, Carly, and welcome to The Asthma Podcast. Thank you so much for joining us today. How are you doing?

Carly 02:20

Well, first, thank you for having me. I'm doing well. It's been an okay day.

Sarah Shaw 02:25

You know what, we'll take okay, right? Take each day one step at a time. That's all we can hope for when we live with chronic illness. So since we're talking about asthma, I want to jump into talking to you about like what your earliest experience or memory you have of asthma is or was.

Carly 02:44

My earliest experience is not the same as my earliest memory. So I was actually born with asthma. But I guess the earliest experience I had with it was during labor, my mother had an asthma attack. And so that kind of, you know, propelled things forward. But yeah, but my earliest memory would have to be I was fairly young, I probably about six, and I had an asthma attack. And so that was like, the one thing I remember. I was at school, and going through, you know, the motions of, you know, I can't breathe, we were in gym. And so it was, or PE for some people, but we had just finished some sort of activity. And we were sitting down, and I couldn't catch my breath the way that normally I would be able to, and you know, something wasn't right, obviously. And it kind of went on from there. You know, trouble breathing, people kind of coming in asking me, am I all right, and wheezing and that type of thing.

Sarah Shaw 02:59

That must have been pretty scary for you at such a young age to you know, be struggling to find breath and you know, your peers coming around you asking you if you're okay. Do you remember what you were feeling at that time? For me, it's hard for me to remember, you know, anything as young as six years old, but do you remember what thoughts were maybe going through your head?

Carly

I was embarrassed. I was I was embarrassed because it was like, this thing is drawing attention to me what's happening, you know, and that was, like I said, the first memory I have of it, and I'm I don't believe I had an asthma attack prior to them. So, you know, it was a new experience for me, but I had at that time seen others who have had an asthma attack. So I knew what was happening. But you know, I didn't necessarily know how to handle it from the first person.

Sarah Shaw 04:47

Right, right. You mentioned your mom actually had an asthma attack while she was in labor with you. Because of the fact that she has his has a history of asthma, was that something that she had kind of prepared you for so that you knew what you were experiencing was an asthma attack when you had it, or were you kind of caught off guard?

Carly 05:09

I was caught off guard for me to have an asthma attack. Even though I knew I had asthma. She didn't necessarily prepare me. But she had already told me the story of her having an asthma attack. It was kind of a wonky day when she went into labor. So it's like a funny story associated with it. Well, probably not funny to her as she was the one going through it. But you know, now, of course, years later, and even then, you know, she could laugh about it, essentially. But I always remembered the story that she told me and so I knew I had asthma. So it wasn't a surprise on that front, however, that I was actually having an asthma attack was a surprise.

Sarah Shaw 05:53

I feel like when you're experiencing something for the very first time, nothing can really prepare you. Even you know, even if you have all the tools, you're never going to really know exactly what it feels like. I myself do not live with asthma, but I live with other chronic illnesses. And people would tell me what a migraine attack felt like. The very first time I had one was not what I was expecting. So I was very caught off guard. So thank you for sharing that.

So into a little fun theme. So the theme of the campaign that we're doing is called "Love Should Take Your Breath Away, Not Asthma," and I wanted to ask you, what does that mean to you, you know, love and falling in love?

Carly 06:33

Well, as of late, I guess my and I say late, but I guess in recent years, my understanding and experience of love has been different. And so, to me, love is a very intentional thing. It is an action word, it's a verb to me. So as much as it is a feeling and you know, an emotion, it is also something that we do. It's something that set with intention. It's something that we live, it's something that we act out. And so that means because it is yes, an emotion but also, you know, something that we do, we can experience it in a number of ways. And that's not to just, you know, be speaking of romantic love, but just, in general all forms of love.

Sarah Shaw 07:21

Absolutely. All forms of love. Speaking of all forms of love, does asthma ever get in the way of you loving or being loved by, you know, family, friends, caregiver support, does it ever interfere?

Carly 07:33

It doesn't interfere, because where I am on my chronic illness journey, I am to the point where I kind of take precaution prior to something and I'm always thinking heavily about any activity or event I'm going to do because of my other illnesses. And so asthma is also included in that. And so I'm just ever mindful.

Sarah Shaw 07:57

That's good. It's kind of like you have the things in your toolkit to prepare yourself. When you wake up every morning, you get out of bed and you're like, "Okay, this is how I'm going to go through the day," knowing X, Y and Z to kind of like you're saying to because you've already been living with multiple chronic illnesses, you know, ahead of time. But what was it, maybe like before you had the hindsight of living with chronic illnesses?

Carly 08:22

Oh, it was absolutely something that happened to me. Not something that I was mindful of or intentional about circumventing. It was just something that happened, there was no plan, there was nothing was in place. It was like, "Okay, I know I have this thing." That's it. You know that that was it was like, I know I have it. And whatever happens happens, because I guess at that point, I hadn't really outside of having an inhaler, And knowing, "Okay, if you're having an attack, you know, you take the inhaler," the rescue inhaler. However, outside of that, it was like, I didn't know that it wasn't just a surprise thing. You know, because that was my experience. Like I said, that first time that I had, it was a surprise. And so I felt it

was something that you couldn't plan. You couldn't, you know, try and prevent or take steps to alleviate some symptoms, etc.

Sarah Shaw 09:21

Right, right. So you didn't realize there are plans that you could put into place, kind of like what you were saying earlier.

Carly 09:28

And I think with my age, that wasn't even anything I was thinking about. You know, I didn't get diagnosed with other chronic illnesses until adulthood, even though I did experience symptoms before, the diagnosis didn't come until then. And so it wasn't even on my mind to be trying to prevent something. You know, I kind of thought that, you know, "Okay, if it happens, it happens. I have an inhaler. Hopefully I'll remember to bring it with me." You know, that type of thing.

Sarah Shaw 10:00

Right, speaking of, you know, rescue meds and things that can help. Did you know of any other people that live with asthma growing up? Maybe inside your family outside of your family? Was this something that that was discussed about how to how to prepare? Like, how did you get to the point where you knew how to figure out how to prepare for these asthma attacks?

Carly 10:22

So I did know people that had asthma. And it always seemed as if theirs was worse than mine, because they would have frequent attacks. And so it was something that, like I said, I did not even fathom that I had to worry about in that capacity. I just thought, you know, like I said, hey, hopefully, I remember my inhaler, you know, that type of thing. It wasn't something that I was really planning for. And I didn't begin looking at my health in that way, until I was diagnosed with my other chronic illnesses. Because, you know, the flares were daily and in a different capacity, and they actually impacted each other. And once I learned those things, that's when, you know, I was able to take better care of myself in that way.

Sarah Shaw 11:12

Right. So it sounds like you kind of learn by trial and error of figuring out what worked and what didn't work. If we can fast forward to, you know, where you are now, your relationship with your loved ones, how do you and your partner plan for your asthma attacks? Like are there certain special things that they do to help? It's kind of awkward too, when you're in a relationship where you're telling people that maybe don't know about a chronic condition, "You know, Okay, hey, here's something that is part of my life. And here's how I deal with it. And here's how you can do it." Like, are these conversations that you had to have?

Carly 11:50

When it came to my other chronic illnesses, those were the conversations I had foremost. And funny enough, my partner found out I had asthma, kind of happenstance, you know, she heard me mentioning it to someone, and was like, "Oh, I didn't know you had asthma." And I was like, "Wait, I thought I told you that, you know.'

Sarah Shaw 12:10

Did you have to have those conversations with your partner? Or was that something kind of that you said, that was unspoken, that they already knew?

Carly 12:16

I think because they because she also knew someone, you know, knew others with asthma, the what to do is kind of unspoken. However, now, if she hears me wheezing, you know, she, she pays closer attention and things like that. And, you know, she just ensures that if we're doing high energy activity, or something that would be extreme cardio, or something of that, sort it, that I'm pacing myself, and I'm being more careful, because I like to take ownership of my illness, and I'm kind of a control freak about it. And not letting others help me that whole thing. And so she just makes sure that I am using my tools effectively. And you know, that's her way of helping.

Sarah Shaw 13:00

It's so common when we live with chronic illnesses that we've often think that we have to do things alone, we don't need help, or we're so used to navigating the world by ourselves. And it's so wonderful when you have partners, and family members and caregivers or care partners that help that step in and like help remind you not to overdo it, or not to just be like, "Okay, like, you know, how about we you know, we avoid this trigger?" Or, you know, are you sure you're Okay? Or if they're there to like hand you your rescue medication. I know, my partner, she does that for me a lot with my chronic illness. And so I think that it's asthma, chronic illness, like they're a multi person disease at times where you have to let the person that you love and the one that supports you know what's going on, so that they know how to help you help yourself, right?

Carly 13:55

Absolutely. And that's something that is very new for me. And that's not to say that I didn't have a partner before who knew about my illnesses. I didn't have a partner who knew and cared in this way. And when you have that, and you're not used to it, it comes as a shock. And it seems very weird, but one of the things that we hold steady to is because I had a habit of holding information. You know, like if I went to an appointment, not necessarily telling everything as to not worry her and so we have an agreement now that I will not do that, you know, I will be completely honest when it comes to my health. And it's for that reason, it's for the reason of if something happens, you know, she'd be able to maneuver properly to help me and then also it's, she told me something one time that really just blew me out the water and it shouldn't have but it did and she was just like, you know, "You're not responsible for other people's worry. Especially when the thing that they're worrying about is something that negatively impacts you. You're not responsible for that. You worry about the thing. And you let them worry about their worry." That's, that's really nice. Like, whoa. Yeah. And so I have to maneuver with that in mind. And if this is going to be a partnership that, you know, I had to relinquish control in that way, I had to let go of just being the only person, you know, active in my care.

Sarah Shaw 15:32

Absolutely. It's kind of like when you can shoulder the burden with somebody else and make it. It's scary at first, right? Like you're like, wait, know what

Carly 15:42

It is, but it makes it easier.

Sarah Shaw 15:45

Absolutely. Absolutely. I'm so glad that you have that support system, you have that loving, caring partner that wants to help you in your journey. And I think that people can learn a lot about relationships like that, where you're able to have somebody supportive in your life that takes an interest in your health takes an interest in your journey, and is there to like, be a teammate really, to help now all of that. And I hope that for everybody, honestly, that that's something that for sure. For sure. Speaking of, you know, supportive partners and communities being part of the LGBTQ plus community, have you found that that community has supported you in your asthma journey? Or are there other communities that have supported you in your in your asthma journey?

Carly 16:32

I would say indirectly, the LGBTQ plus community has supported me. And the reason I say indirectly, is because my friends have supported me. And they are themselves queer. And you know, so when we wouldn't be going to queer spaces or whatever, you know, they make sure I have everything I need, when we're going out, or, you know, we're doing things and so in that way, they've helped me but it hasn't really been, you know, a focal point, so to speak, we didn't make it a spectacle. But my friends have done over the years, the thing were that they're supposed to do, you know, they're there for me in whatever way I need them. And that does include ensuring that I'm most prepared for, if something should go wrong,

Sarah Shaw 17:19

That's really, really good, really amazing that you have that support system that people that look out for you. I know that too in the chronic illness community that along with friends, there's also other people that get it like, I know that you have a support system within Lupus Chat, do you want to talk a little bit about how they've supported you?

Carly 17:40

Oh, 100%. And it's twofold. Because not only is it Lupus Chat, the community, you know, of patients and caregivers, but it's also the executive team, as I am a member of the executive team, the other three people are three of my closest friends. And it's because of how we take care with each other in that way, you know, two of which are patients themselves. One is a caregiver. And so we're there for each other in that way. And they have been extremely supportive, when it comes to any illness that I have. And the same goes for Lupus Chat, the community because I have the ability to, you know, not only ask them questions about, you know, their experiences with lupus, but also with any other chronic illness or condition that they may have. It's been extremely helpful. And you know, it's one of those things where it's always good not to have to explain it to people who already get it. That's like a second layer of comfort. And so that's something that I get to, I'm lucky to experience.

Sarah Shaw 18:49

It's like that unspoken, you know, language that we all kind of speak. It's really truly amazing. Where you don't have to explain away oh, I'm doing this because of X, Y, and Z, or I need to sit down because, you know, I have I walk up these steps and they just get it. They just understand.

Carly 19:06

They get it. Yeah. And sometimes what I what I find most interesting, is, as much as I'm an advocate, and as much as I'm knowledgeable about all of my illnesses. Sometimes I find them making me look out for things that I hadn't even thought about. And I'm like, oh, yeah, I should probably pay attention. Yeah, that type of thing. So that's helpful as well.

Sarah Shaw 19:27

Yeah, I absolutely. Absolutely agree. I think what maybe the audience would like to know is, what advice do you have to share for somebody that is maybe just starting out on their asthma journey, maybe somebody that's new and is scared and trying to navigate this new chronic illness? What advice do you have to share from the things that you've learned on your journey to other people?

Carly 19:54

I would say first and foremost, pay attention to your body. Listen to what it's telling you. And be mindful about the activities that you do and when, and the environment because there are so many different things that can trigger you, you have to just make sure you're doing everything you do with intention. And I know it can feel cumbersome at times, "Why do I have to think about this? Why? Why can't I just be quote unquote, normal," but it's in your best interest because number one, you need to breathe. That is, you know, something that we all need. But as we are also now navigating pandemics, with asthma. But just thinking about COVID, and things like that, that complicates things, you know, I can speak from experience as how that has also impacted my asthma and my experience with that, and so, just being super mindful, paying attention to your body, being honest with your loved ones, like I said, that was one of the most important lessons that I learned in recent years, was to let go of the control, be honest. And that's even when you're going through your acceptance process with, you know, your disease, with your illness, because there are, you know, there are people Yeah, they say I have asthma, but I don't, I haven't had an asthma attack, or you know, and you're just kind of glib about it until you can't be. And so I think it's important to be honest with yourself, be honest with others, so that they can help you, as you kind of navigate your journey with this and understand that it's a journey. What your asthma looks like, now may not be the same that it's going to look like in some years to come. And so it's important to document those things. It's important to also be honest with your physician, and, you know, have open communication with your entire healthcare team. But also you want to be letting your employer know certain things as much as you can without, you know, that you feel comfortable with, but just enough so that, you know, should something happen, they're able to help you.

Sarah Shaw 22:06

You just dropped so many nuggets of wisdom that I think anybody just starting out on their journey can really appreciate and take to heart is, you know, it's like I mentioned, it's probably really scary when you are diagnosed with something new, or you're experiencing something new and you don't really know where to turn what to do. And I think that you really shared a really authentic way to navigate and

empower yourself to do what's best for yourself, to get you to better treatment and better care. So I want to thank you. Thank you, Carly, for joining us today, sharing your nuggets of wisdom. I know that I appreciate it. I know that our listeners will really appreciate that. And thank you for joining us today.

Carly 22:52

Thank you so much for having me and for having the space, you know creating the time for this.

Sarah Shaw 22:57

Absolutely. Thanks for listening to this special episode of The Asthma Podcast, where you hear about the stories of LGBTQ plus asthma patients. We touch on navigating love, relationships and their health. If you liked this episode, please give it an honest five star rating and subscribe. Once again. I'm Sarah Shaw and I will see you next time. This episode of The Asthma Podcast was made possible with support from Amgen and AstraZeneca, sponsors of the Global Healthy Living Foundation.

Narrator 23:37

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