

# Heather Malkawi

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Austin, Austin Presbyterian Theological Seminary, Church of the Nazarene, Disabilities, Discernment, Epilepsy, Flint, Medical marijuana, Medication, Michigan, Seizures, Seminarians, Texas Freeze, Unitarian Universalists, Volunteering, Youth groups

## 🗣️ SPEAKERS

Sopphey Vance, Heather Malkawi

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- S** Sopphey Vance 00:06  
I'm Sopphey Vance, and I'm interviewing Heather Malkawi for the Texas Freeze collection for the Institute for Diversity and Civic Life here in Austin, Texas. Heather, say hello.
  - H** Heather Malkawi 00:21  
Hello.
  - S** Sopphey Vance 00:25  
Heather, and I'm Sopphey. So here we go, Heather. To start, Heather, tell me a little bit about yourself. What were some of the formative experiences growing up that made you who you are?
  - H** Heather Malkawi 00:42  
My name is Heather Malkawi. I am originally from Flint, Michigan. That is also known as Buick City up in Michigan. Let's see. Most people are aware of Flint, Michigan now these days as the place with, "Oh, that's the place that has the bad water, huh?" Yeah. Some of the things that make me who I am.



Sopphey Vance 01:25

So you grew up in Flint, Michigan. Did you go to church? How many siblings did you have?



Heather Malkawi 01:39

Yeah. So I am actually the middle child of three. I have an older brother, who is six years older than me. I have a younger sister who is about three years younger. We grew up in a Nazarene church, and I am a third-generation seminarian. My dad was a Nazarene minister, and so was my grandfather. That was definitely a fun experience. A fun little tidbit, it was my mother's father and my father they went to seminary together, so that was a fun little experience for my mom, I'm sure. For me, I grew up, like I said, the Nazarene church. I guess to me, I say the typical church experience, youth group, Sunday morning, Sunday night church, went to church on Wednesdays. Everything kind of centered around the youth group. We had a huge youth group. Even to this day, I still keep in contact with my large group of friends from there. I definitely live a different life than they do, we have different - I don't want to say values, but politically we're very different. But we still keep in contact.



Heather Malkawi 03:33

Yeah, growing up, I went to church. It was a very large church, but it was out in the country. It was about a half hour away from where I lived. Like I said, I lived in Flint, Michigan, and it was a very large, large city at one point. It is starting to dwindle after the water crisis from 2000. I want to say I think it was 1819. Yeah, the numbers are starting to dwindle. But when I went there, it was a fairly large city. I grew up there, and I'm going to say right around 2004, I left. I moved to Chicago just because Flint had really started losing some of the number of people and such. So I moved to Chicago and started work there. I lived there for about ten years, and then I moved down to Austin, Texas.



Sopphey Vance 04:50

Tell me more about life in Austin. Was it different in any way, culture-wise, anything-wise?



Heather Malkawi 05:01

Yeah, so I moved down to Texas actually, to be closer to my son. My ex-husband had guardianship of my son after I was diagnosed with epilepsy, and I had uncontrolled seizures. I had to make the decision to give up guardianship to my ex-husband, just so that that could be a safer place for him. When I did that, my ex-husband moved down to

Texas from from Illinois, where we were living at that time. At that point, I had made the decision to eventually move down to Austin, Texas. Once I was able to get down here, it was definitely different. Austin and Texas [are] very different. I remember the first time that I caught myself saying the word "y'all" 'cause I can tell you, growing up, I never knew exactly where I was going to be when I grew up, but I could absolutely tell you, I was never going to live in Texas. That was one thing I knew for sure. I was never going to live in Texas. Here I am. Living in Texas. But I remember the first time I said "y'all," and I put my face in my hands and I was like, "What have I done? I'm living in Texas." But I like it here.

**S** Sopphey Vance 06:59  
That's very exciting. Welcome to Texas.

**H** Heather Malkawi 07:07  
[laughs] Thanks.

**S** Sopphey Vance 07:09  
You mentioned epilepsy. What's it like being a seminarian - third-generation seminarian, that's already a lot of pressure - but a seminarian with epilepsy if you want to expand on that a little bit more.

**H** Heather Malkawi 07:27  
Yeah. Honestly, I had to think about whether I would be able to go into seminary. People talk about discernment when they decide they're going to go into seminary, and I feel like I had an even larger discernment process. The idea of seminary was literally just thrust upon me. I can tell you that when I was speaking with my minister, I took a sermon writing course, and had a few questions about a sermon that I was writing, and I was stuck. She just stopped and asked me a question of, "Hey Heather, in ten years, can you see yourself being a minister?" I was just like, "Yeah, I think I can." She was like, "Okay. Well, what about in ten years, can you see yourself not being a minister?" And before I could answer the question, I just burst into tears crying. I couldn't even answer the question. She just stopped and was like, "I think you've got your answer."

**H** Heather Malkawi 08:51  
So I didn't even have to really think about whether that was an option, but the discernment process was really, "Can I do this with epilepsy?" Because not only do I have

epileptic seizures, but I also have non-epileptic seizures. Not many people have both. I have to keep track of medication, I have to keep track of stress, I have to keep track of sleep, I have to keep track of so many factors that I don't necessarily have control over. If any one of those, let alone a group of those factors, are out of whack, I can wind up having a seizure. I don't necessarily have the the typical grand mal seizures where all of a sudden you just start flopping around on the ground. There's forty different types or more of different types of seizures.

H

Heather Malkawi 10:03

For me, I can't speak, I just freeze. It's like being trapped in my own body. I can't do anything, and I can't tell anybody. It just starts getting worse and worse, and that's the problem is that people just keep on doing their own thing around me, and I can't make anybody stopped to help me. Because if I've let it go on for too long, or if I haven't done anything quickly, if I don't have somebody that's around me that knows what's going on, nobody can really help. I really have to advocate for myself ahead of time, and train people, and let them know, "These are things you have to look for, because you may not know that I'm having seizures. And if it goes too long, it can cause brain damage, it can cause other damage, it can cause so many things that can happen." So for me, before I just had to worry about myself. And if I can do that, then I should be okay, and I can take care of my kids also. Well, can I really go into parish ministry? What happens if I get worried during a sermon? What happens if something else happens, and all of a sudden, I can't speak? If my only job is to do a sermon on Sunday, and I have a seizure, either during service or before service, what's going to happen?

H

Heather Malkawi 11:46

These are all things that just kind of have popped into my head beforehand, and I had to really go through a discernment process of is seminary really there and the right process for me? So far, things have just opened up. Doors have opened up, in the UU denomination, there's more than just parish ministry. Going through that search process, learning how many different types of ministries there are, learning how I can go through that process and all kinds of different avenues is amazing. It's exciting. Coming to Discovery Weekend here at Austin Presbyterian Theological Seminary, or APTS, was amazing. It's a whole weekend-long experience. I missed the whole first day, I never got to see classes, I never got to see the classrooms. I never got to see any of those things. But I got to have dinner with and listen to the President, I got to sit down and talk to a few professors and a couple students. The next day, I got to have an interview. That's about it. In talking to just a few people, there was just so much overwhelming joy, and just this feeling of, "this is right." I just felt that guidance.

H

Heather Malkawi 13:36

It's amazing because I made a promise to myself that if this is what I'm supposed to do, I have to stand up for myself and advocate. I have to be honest, and I have to always show up. If somebody asks me questions, if somebody asks about what I'm doing, if somebody asks about what my ministry is, then I have to be honest. Now, this is a few years ago. For me, advocating for legalization of medical marijuana for epilepsy was true to my heart. It was something that was big on the docket, particularly here in Austin, Texas. It needed to have a lot more research, particularly with CBD implications and the work for that type of medication, because it can be very, very incredibly useful for medicinal purposes for epilepsy.

H

Heather Malkawi 14:47

Who talks about that stuff when you go for seminary interviews? Seriously, who talks about that? I do. When you sit down and you've never met anybody before and you just start talking? Apparently I do. Because I didn't even think about it, they started asking, "What is it that you want to do?" "Well, I want to use the dual degree program, social work and divinity, marry those two degrees together, so that I can help legalize medical marijuana for people who have epilepsy. Yep, that's what I want to do." I literally sat there and was just like, "What the heck did I just say? Holy crap. Anybody write that down?" I didn't know that I was going to say that at all. It just scared me, because I had no clue that that's for sure what I wanted to do. I was sitting at the table with Professor David Johnson and Sarah Gaventa and another one of the students who was a dual degree program student, and I don't remember who who else it was. But at the time, I didn't know that those were the people. Another dual degree student. I didn't for sure know that that's what I wanted to do, but I was placed at the table with the right people. I still am dumbfounded that that all fell out of my mouth. It was overwhelming, and then I was like, "Well, I'll do the interview. What the heck, why not?" It just fell out of my mouth again. So I was like, "I guess that's what I want to do."

H

Heather Malkawi 16:26

I was accepted. I couldn't believe it at all. Since then, CBD medication has been federally regulated and medical marijuana - as well as independent use, but whatever - for many states. So working with family of those who have epilepsy has quickly become an additional thing that I am wanting to work on. It's funny that we talked about this today because I was taking my son home today and was listening to the news. Just today, there's a group who is working on getting - it's not family medical leave, but it's very similar. It's called the Care Now Act, I believe. It's getting medical leave approved for everyone to be able to get time off of work paid, so that you can care for those who need

to be cared for. It should be approved for everyone no matter what your job is. Which absolutely dumbfounded me today. It just dumbfounded me because I feel as though every time I get this passion of what it is that I'm needing and wanting to do, I don't want to say that people are just taking my my soapbox out from under me, but [laughs]. I was like, "Wait a second. That was my idea about six months ago." I have to keep it in my heart that, "Okay, I must have started talking to the right people. Alright, keep pushing. Let's go." I don't know if I've answered your questions. I've just kept talking.

S

Sopphey Vance 18:34

Yes. It's amazing. You mentioned UU. Is that the denomination or church that you attend currently?

H

Heather Malkawi 18:42

Yes. So UU is Unitarian Universalism. That is the church that I attend. And Unitarian Universalist is the denomination that I intend on getting ordained in. Sometimes because of the epilepsy, words either don't sound right, or they come out of my mouth incorrectly, so I apologize. I like to make up my own words. Let me know if they're not correct.

S

Sopphey Vance 19:17

I think you're doing a great job. I want to talk a little bit more about your experience during the quote unquote "the freeze" during the Winter Storm Uri here in February. Do you have any adventures? Where would you like to start? This is your story.

H

Heather Malkawi 19:39

Sweet Baby Jesus. That time was crazy. It was a whirlwind of adventures and a horrible time for me. I am on a number of medications for my epilepsy. One of them is a medication called Epidiolex. I've been on it for probably three years maybe now. It's only recently becoming much more known. It is one that's usually only prescribed for kids, and it's only been approved by the FDA for certain types of epilepsy. It's very difficult to get approved for it, but it has been very, very effective for me. I had to go through many, many hoops, and go through a lot of paperwork and authorization and everything. I had to fight with insurance companies in order to get my medication. I have tried over fifteen different medications and many different combinations of those medications to find the right cocktail that would work for my seizures. It wasn't until I tried Epidiolex, which is a federally regulated CBD medication. It does not contain any type of THC content. THC is the part of the hemp plant that gets you high. It only contains the CBD part.

H

Heather Malkawi 22:10

But because of the regulation and how highly regulated it is, I can't get it at any pharmacy. At the time it was only distributed by manufacturers. So it is mailed to me every month. Now, in February because of the freeze, all mail was stopped. Everything was stopped, and I had no access to my medication. Without my medication, I have seizures. Because of that, I had run out. I knew that I was going to be running out. I had to start rationing medication and pulling it back, not taking enough, trying to use different medications for as long as possible. It wasn't just during the time. The snow was there for just maybe a week. But there was problems with the mail during the time that there was snow, the snow buildup, and then even the problem with all of the mail being behind and getting there. My mail had to be sent two different times. It got lost in the mail.

H

Heather Malkawi 23:46

Keep in mind, because it is federally regulated, it's supposed to be signed for. I live on campus. I live in an apartment where there is not an external door, you have to have a key pad in order to get in. FedEx has to go to a main lobby of a campus building, and we can only pick up mail during weekdays, nine to five. When the school shuts down, so does the campus building. So therefore, we didn't get any mail, and I couldn't have it delivered to me. So I couldn't get out of the building. I couldn't go pick it up anywhere. Even if they had it left at a distribution center, they couldn't locate it. It was lost somewhere. They tried to have it sent to me a second time, but we still had the problem that it couldn't be delivered directly to me. So at one point I sat outside of my building while it was freezing, trying to just wait for any FedEx man to come and drop it off to me. I went for probably three weeks without my seizure medication. It wasn't until they tracked it directly to a distribution center, and then I had to go there to pick it up.

H

Heather Malkawi 25:18

It was very, very difficult for me during the Texas Freeze just personally, for my epilepsy, because I had to manage medication. I had to try and manage any stress. I had to manage sleep. I had to manage everything that was going around me, and any type of stressors amongst some sort of crisis. We didn't have water. Thankfully, we were very, very lucky that in the building I was in, we had electricity. But we had to minimize what we had, so that we could help save it for everybody else. But we didn't have any water. I had family, I had friends that were in buildings next to us across the city that didn't have anything. I had a friend who went almost an entire week without electricity or water, and they just stayed in their house. I had somebody else who literally had their garage and car broken into, and since it was broken into, it was just wood. Everything was stolen. So they just started burning that inside their house, so that they could try and keep warm.

H

Heather Malkawi 26:51

The most frustrating part was that for most of that freeze, because it was during COVID, here on campus, we couldn't let anybody in. I had heat, I didn't have water, but I had heat. I had a three bedroom, huge living room, and it was just me and my niece. Finally, I remember just writing campus and saying, "This is uncalled for. We have to let people in." Eventually, they said, "If there's people that need in, that we have to take safety over precaution," which was the right call. But it was a hard call. I know it had to be. That was really, really hard in the middle of a semester, having to take classes, write papers, and knowing that all of this stuff during COVID - it was craziness. To think back, all of those things that were going on, it was cold, but we were numb. I was absolutely mentally, physically, emotionally numb. And I was the adult in the house. I had teenagers. I have no idea how we made it through. No clue. But I know that there are people out there that were helping and doing everything that they could.

H

Heather Malkawi 28:57

I know that for myself, I had to start feeling things. At my church, the Unitarian Universalist Church is up in Cedar Park, which is probably a good twenty, thirty minutes away, because we moved downtown from where we were to come to school. One of one of my friends lives across the street from the church, and they were like, "Wait a second. I have water. I have electricity. If I do, the church does. And it's drinkable water. We're handing out water. Let's go." So my church literally was like, "If you need water, you come get water. Bring your buckets, bring your whatever, let's go." So there was probably a Friday, a Saturday, and a Sunday that everybody was there. I took my kid and myself, and I took a couple other people from seminary that wanted to go, and we just started handing out water. Whatever buckets you have, you bring them, and we will hand you water.

H

Heather Malkawi 30:12

I think that was the Friday, and then on Saturday, people that night heard what we were doing. So people from the church started bringing things. We had diapers, we had feminine products, we had food. We wound up with tables of things. If you need any of these things, take them. It wound up being kind of this community cupboard of, "Come shopping. If you need something here, it's not just water, take these things too." It just wound up being more. We just started handing things out. Sunday, I took more people with me. We had some people from campus here that lived farther out in the country. They couldn't get in. They had twelve foot high, deep snowdrifts. Some of the people that



couldn't get into the city to come get these things. We were hearing from other people that, "Some people need these things. Some people need these things. We're not getting as many people coming in on Sunday." "All right, load up the car, let's go." We went out. We were like, "Field trip time." [laughs] We took everything out to other people. It was good. That's what I needed at that point, is to just feel something and get out and go do something. That's what I needed. I don't care if you don't need diapers, I'm bringing you some. And here's some chocolate.

S

Sopphey Vance 31:59

That's a very powerful story. Do you have any tips for Texans in the case of another winter storm?

H

Heather Malkawi 32:29

Ah, gosh. I don't know. I mean, honestly, I think the best thing that we can do - I think it's always good to have a coat and have some of the the warm things on hand. Just in case. Yeah, it's Texas and right now it's set on melt. We have to take things one at a time. One day at a time. Me personally, as one person, I don't know how to fix it. I just take things one day at a time.

S

Sopphey Vance 33:38

That's still a very powerful tip. One day at a time. Anything else to your story, or your experience during this winter storm? Something that you feel that needs speaking of.

H

Heather Malkawi 33:59

Don't be afraid to ask for help. Don't be too prideful to take help. I think that's advice that I needed too.

S

Sopphey Vance 34:13

Wow. Well, thank you so much, Heather. I will stop the recording, and thank you for sharing your story.

H

Heather Malkawi 34:21

Thank you.