

Optic Nerve Glioma with Karina Smith and Michelle Culbert

Speaker Key:

VO Voiceover

CB Chantal Boyle

LS Lynn Smith

KS Karina Smith

MC Michelle Culbert

00:00:00

VO

Welcome to The Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

CB

Welcome to The Sunflower Conversations. My name is Chantal, and I am joined by my colleague and co-host, Lynn. Lynn is based in the US. How are you doing, Lynn?

LS

I'm doing very well, thank you, Chantal.

CB

Our guests today are Karina Smith and Michelle Culbert. Both are from South Florida, and they both have optic nerve glioma. It is a rare eye condition affecting the sight and typically affects young children. So, we are going to find out a lot more about that today, as it is a rare condition. Lynn, how is everything going stateside?

LS

Everything is going great stateside. We're getting a lot of momentum coming here for the Sunflower, and I'm looking forward to talking to these ladies. Karina has been helping us spread the word on the Sunflower, so we're excited about that.

00:01:24

CB

That's brilliant. And that's one of the things, isn't it, that we really enjoy, I think, is that once somebody knows what the Sunflower is about, then they're very happy to become an advocate, to share what the message of it is and how it can support people with non-visible disabilities, and also support people who don't have disabilities to be more open and have their eyes open and be more willing to offer that support, and maybe not jump to conclusions and judgements when they interact with people with non-visible disabilities. So, I'm really pleased that the relationship has already kicked off with you two.

So, let's not waste too much more time. Karina and Michelle have become the closest of friends through their shared experience of optic nerve glioma, and they are passionate about raising awareness of it and building a community to provide support to one another. I guess, probably, one of the things we might just want to touch on here is how you two have become friends, because America is a very vast country and I know that this is quite a rare condition. So, how did you two meet one another?

00:02:41

KS

So, I started posting on social media about my journey, and, a few months after, I got a DM from Michelle on TikTok saying that she had the same condition as me.

CB

And then you bumped into each other. Is that right?

MC

Yes, so, I was recently diagnosed, and I was searching on social media, which was a mistake. Very scary stuff. But I saw someone that looks normal, like me, and talking about it. And I messaged her and asked her where she lives, and she lives 15 minutes from me, and we were almost diagnosed five, six months apart, and we have the same exact doctor all the way in Miami. So, we stayed in contact, and we actually started the IVF journey at the same time, and we were messaging each other every day, and she actually needed some injections, and I had some left over, so that's actually how we met first in person. I gave her some injections for the IVF.

CB

What a great first meeting.

KS

I want to add that, at first, when she messaged me, I thought it was a scam, because this is so rare. This condition, this tumour is so rare. I thought someone was playing a sick joke on me. And I was like, this is really rude for someone to message me and act like they have this and they live close to me. So, when I actually met her in person, I was like, this is the real thing, and I did it. I found that one person. You know what I'm saying? So, that felt really good to do. And so, yes, that's us now, and we just had dinner last night, and we're here now.

00:04:22

CB

That is an amazing story. Karina, can you tell us, what is optic nerve glioma? And what, if any, are the stats around it, the amount of people it affects? I mentioned that it's a childhood disease, but can you explain a bit more about that?

KS

Yes. So, the optic nerve glioma is a type of brain tumour. So, this brain tumour is encapsulated in our optic nerve, so in that chiasm. And so, what that means is, your optic nerve is basically telling your brain what you see. So, when that's blocked, your brain isn't able to communicate with what you see. So, our vision is impaired in one of our eyes right now.

So, the disease, or the tumour, is typically found in children. The average diagnosis age is eight and half years old. So, we found ours at age 24 and 26. And it was sudden onset, so, just going with 20/20 for me, and then the next morning having impairment was really monumental, was changing for me. But it's very rare to find an adult. 75% by the age of ten are diagnosed. So, definitely something that's found early on in life, and it's treated differently when you're younger. So, they have a set remedy for that right now for kids. Chemo and radiation, that's the go-to.

But for adults, it reacts differently to our bodies. So, they didn't have any treatment plans for us. They gave us a set amount of options to do our own research, and there's very little research, because not a lot of adults have it. So, that's kind of the confusion and the frustration that we put our heads together about and luckily had each other for.

00:06:21

CB

Yes, I'd imagine that's a really fearful position to be in, that you're making decisions about your eyesight, the treatment, which we'll come onto. But before we get to that, Michelle, can you tell me how it affected you, and how did your symptoms start?

MC

I already had... I wore glasses and contacts, so my eyesight wasn't the greatest. I noticed, woke up one morning, very onset, like Karina said, and my eye was much weaker. So, I went to the doctor, and he said, don't think anything of it. One eye is going to be weaker. And this was months before I was officially diagnosed. I got a second opinion, and the same thing.

That first opinion was from an optometrist, you know, your regular eye exam. That ophthalmologist shined a light in my eye. My right eye reacted perfectly, but my left eye would not retract to the light that was being shined in it. So, he said, there's something blocking your eye. There's something behind your eye. We're not 100% sure what it is, but you need to go right now to get scanned at Bascom Palmer in Miami.

So, I also had colour loss along with the blurriness. When I would just look with my left eye, any reds would look orange, and everything in general was very yellow, and it's still like this today. But that's what I noticed when I woke up, the blurriness and the colour loss.

00:07:48

CB

And Karina, you said that it was suddenly overnight for you, as well. Did you also have the colour issue that Michelle...?

KS

I don't have colour loss, but I don't, no. I think, Michelle, correct me if you're wrong, yours is blurry vision and colour loss?

MC

Yes.

KS

Mine is... So, imagine the square of our screens cut in half and the bottom half blacked out.

CB

Okay.

KS

So, out of my eye, I can see like that. So, I only see the sky and the trees. And then, anything under me, I don't see out of just one eye.

CB

How does your brain recalibrate to that?

KS

That's funny you asked that. The first time I went to the beach after I realised my vision is gone there, I was looking at the landscape, and I got kind of nauseous because I was not comprehending that I couldn't see what I've seen before. But I would say I adapted pretty quickly to it.

MC

Yes, your strong eye compensates for the loss of the other eye. So, we've gotten used to it, but it's noticeable just looking out that one eye, and the peripheral is pretty much damaged. And, with our head movement, we have to turn our heads all the way. And me and her both bump into stuff.

00:09:21

KS

Yes, you bump into stuff. If you're in a crowd, good luck, because you'll get trampled. If anyone is walking on my right-hand side, anyone sits next to me and hands me a hotdog or is waving at me, I will not see them, because it's blind in my peripheral.

CB

Yes. Did you ever have a period or a stage of time where you tried to keep your eye closed whilst you adapted to this sudden change, this sudden onset of eyesight loss?

MC

I tried many different things. I even wore an eyepatch for some time. I would put an icepack on my eye. I would try looking with just my right eye, because we didn't know. Does it cause muscle strain? Does it cause eye strain? No one told us what to do about it. They just said, okay, go home and see what happens, basically.

CB

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So, because it was sudden onset, does that mean that both of you took swift action to go to your... You called it... I can't say it. Optometrist?

MC

Yes, so, when we went to Bascom Palmer, we actually saw a neuro-ophthalmologist. That's the doctor that they have at Bascom Palmer, and we both still have the same one, same doctor.

00:10:55

CB

And they weren't sure what they were dealing with to start off with?

MC

They diagnosed it, but because they can't do... They shouldn't do a biopsy. Karina actually got a biopsy. It makes your vision worse. And Karina can talk about her biopsy, how it was.

CB

What happened there, Karina?

KS

Yes, so, I was kind of the guinea pig. So, I went to Bascom Palmer first, before Michelle. So, I was the first adult that they saw with the optic nerve glioma. And so, first of all, they didn't diagnose me for about four months. So, I was undiagnosed for about four months. That's why they did the biopsy. You're not supposed to do a biopsy right off the bat because it can impair your vision more, which it did for me. At first, I had just blurry vision, and now it's blindness from down, right.

So, I was, I would say, the guinea pig. They thought it was some sort of... What's it called? Like an anti... What was it? They thought it was some sort of... What was it called, Michelle? Disease that's like...

LS

Autoimmune.

KS

Okay, yes. They thought it was...

MC

They thought it was Lyme disease.

00:12:14

KS

Yes, autoimmune disease or inflammation. So, they started me with steroids. They put me on hundreds and hundreds of steroids, pumped it through my veins five days straight. Nothing went down, no swelling, nothing. So, they're like, okay, it's not inflammation. What's next? Biopsy. Okay, the biopsy actually came back inconclusive, so they didn't even get anything from it. So, that was

inconclusive. They did a CT scan of my chest. No autoimmune disease. They did blood tests. No autoimmune, no anything out of the ordinary. Everything's normal.

I finally did a PET scan at the end, and they said it's something. We don't know if it's a glioma or a meningioma. It looks like a glioma, so we're going to go with that. It hasn't grown. So, gliomas typically are more slow growing. So, they levelled me a Level 1, 2-type tumour, Grade 2. And so, they kind of just went with that and said, we'll test you every three months through an MRI and see if it moves, and if not, after a year we'll go every six months. So, that's where I'm at now.

CB

Every six months?

KS

Every six months.

CB

Is it cancerous, the tumour?

MC

Well, I'd like to say no, but it is cancerous. Any cell that multiplies is considered cancerous. There's grades of tumours. Like Karina just said, ours is a Grade 2. I think it goes from 1 to 4, 4 being where the cells are very abnormal and malignant. Ours is on the Grade 2 side, so it's not the best thing to hear, but it's also not the worst thing to hear.

00:13:56

But yes, it is considered cancerous in the fact that it could grow. But Karina also mentioned that it is encapsulated in the nerve. So, the chances of it metastasising is pretty low. But then, there's a lot of questions of, when will it grow? What does that look like? Will it remain stable? And that's what the doctors don't know.

CB

And they can't remove it?

MC

One doctor told me, if you had that removed, the surgery would be morbid.

CB

Okay.

MC

That was his exact words, and that really scared me. But that was one doctor's opinion. It just hasn't been done. Maybe it has. Maybe it's been done. But we can't find those people. It's so rare. And I know Karina has talked to a neurosurgeon, and they just don't know what it will do to the actual eye. Would we lose our eye? What will the movement look like? Would we need to get a fake eye? That's the last option.

So, with the treatment options, like Karina said, they just said pick and choose. They gave us three options. Four, I guess. Radiation, immunotherapy, chemotherapy, or leave it alone, depending on where we're at. So, for me, similar to Karina, I was on 100mg of prednisone five days in a row.

CB

Which is...

00:15:29

MC

And then, let's just check every three months.

CB

Sorry, what is that?

MC

Prednisone?

CB Yes.

MC

It's a steroid that decreases inflammation. So, if you have congestion in your lungs, you'll take a steroid pill to decrease the inflammation in your body. So, they thought that maybe this glioma was inflammation. They were just trying anything they can on us. But after the three months for me, it did grow a little, and they don't know why. I have talked to other people that have this, and they said that it could have been the prednisone that caused the tumour to swell. So, that's a possibility. But then I had to quickly do IVF, and then I did proton beam radiation. But Karina has a different treatment story.

CB

Can you explain what proton beam radiation is?

MC

Yes. So, there's two types of radiation, regular radiation and proton beam. It's hard to find a proton beam centre. I did mine with the South Florida Proton Institute in Delray, Florida. And proton beam is different from regular radiation, because proton beam is very specific. So, if I were to get regular radiation, it would be on my whole brain, or just that area, but proton beam is that specific area, little millimetre in front of the tumour and behind the tumour. So, it's very specific and it's less toxic to the rest of your brain. So, I did 30 sessions, Monday through Friday, for six weeks.

00:17:07

CB

Is that painful?

MC

I didn't feel anything during while laying on the radiation table. Mentally, that's a whole different story. But I actually smelled the radiation.

CB

Oh, really?

MC

because it went through my temple, and it's so close to this whole area in your brain that's all connected. I smelled it, and I still remember the smell to this day. I asked my doctor, and he said only 10% of people smell it.

CB

What would you describe it as?

MC

When I get a smell of cleaning products, like bleach, it reminds me of it, and it's very uncomfortable. But my doctor said it's the ozone smell, the ozone from the radiation.

CB

Oh, gosh.

MC

Yes, it's bizarre. But that was my journey. I did the proton beam. And from there, it's remained stable, and now me and Karina are on the six-month watch monitor for our tumour.

CB

Okay. Lynn, you were going to ask a question, I think?

00:18:11

LS

I just wondered if you know of any other people in your area that have this, or is it more... I know you said it's prevalent in kids. How many people are going through this in South Florida that are at your doctor?

MC

Probably just me and Karina.

KS

Yes, we are part of different Facebook groups with adults that have similar brain tumours, and none of them identified as an optic nerve glioma in Florida. We have had different people reach out throughout the years. I was telling Chantal that it was at least five people within the past two years or three years that have been going through this have reached out to me, and it's people from across the world. One in Nepal, one in Germany. One in Florida here, Michelle. And a few others have reached out. I didn't get their location. But it's trickling in one by one, and they're from all over.

So, it just goes to show how rare it is. It's not like I posted and everyone's joining groups and we're meeting up and hanging out. No. I'll get a text one night, and I'll be like, Michelle, I found someone else, or someone else found me. And then, four months later, someone else found me. So, that's how it works with us.

LS

I think you two found each other is amazing. I'm sure it's great to have that support behind you and you guys have each other.

MC

Can't do it without her.

00:19:38

CB

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I guess that brings us on to our next question. How has this process and journey affected you both, both of you, psychologically? What impact has it had socially? And has it affected your work?

KS

So, I guess I'll touch on my three, how it affected me in those ways first. You said psychologically first. So, when we were in the dark of what this was for the good four months, I was feeling it. I was not social. I didn't want to go out. I had just had surgery on my eye, so I was embarrassed, and I was afraid of my vanity. Oh my gosh, I've never shared this before. Actually, I had my surgery done on my eyeball, which is so disgusting to me to hear or to think about, but they had to take out my eye and move it to the side and take the biopsy.

So, it was shortly after Halloween, and I was in a store, and a guy was like, do you still have your costume on? I was like, no, I have a brain tumour. And that just goes to show, hidden disability right there. So, that really made me go into my shell. And for those four months, I had to unenroll out of school. I was in my Master's programme. So, I didn't know what that was going to look like. And I'm first generation, so I was really happy to graduate.

So, I kind of went into my shell, and then, when we did get the diagnosis a few months later, I was like, okay, now I know what it is. I'm feeling better. I was able to get back into school. I finished on time. And my support grew. So, that was helpful for me. I would say also, psychologically, I am a therapist, so I was able to use what tools I was learning to help calm myself down, like mediation or prayer or just anything mental health I was trying on myself. So, socially, oddly enough, I lost quite a few friends.

00:21:49

CB

Did you?

KS

Yes. One girl didn't invite me to her graduation, and I was like, you know I'm going through this. I would love to be out and just feel included. And we weren't seeing eye to eye with that, and so I was kind of shocked. And then, another friend of mine had said, she's faking.

CB

Oh.

KS

Yes, because I had started a GoFundMe because I was told how much my immunotherapy would cost, and I just needed that support. I was in a car that had no blind spot monitors or any safety features, and so I needed that help, and I made a GoFundMe. And shortly after, talking happened, and she's faking it, and whatnot. So, socially, that was tough.

But I would say workwise was the first time I'd ever taken off work since I've been working at age 15. So, it was new to me. After I graduated my Master's, I took six

months off, as well, which I was not planning to do, but I know I needed that. I knew I needed that. And so, I would say it really taught me how to prioritise my health and wellbeing in my work area and workspace.

CB

Yes, that is a really tough, tough journey that you've been on. The physicality of what's happening to you, but emotionally to have people doubting you and saying negative things and casting aspersions on your character and who you are, I can't imagine what that must have been like. Really hard.

00:23:25

KS

Yes, it was tough. It was tough. I suffered a breakup during it, which no one wants while you're being diagnosed with cancer. But I would say it taught me that the people who did come into my life after love me for what I came with and what I have and who I am. And so, I'm really lucky for the relationship I'm in today, my partner today, my friends today, and everyone who's here in my corner now, because that's who is supposed to be with me.

CB

Who's supposed to be with you, yes, and that's true. And I guess it was fortunate, in a sense, that that's your training with regard to mental health and wellness and understanding how that can have an impact on you physically, as well, if you can't get that in check. Michelle, for you, what was your journey like?

MC

So, ever since I was 18, I've suffered with generalised anxiety disorder. And that stemmed from severe health anxiety. So, whenever I felt something in my body, I would always assume the worst. That's just how my brain worked. But I've been through therapy for it, and it was better.

But ultimately, a big fear for people who have hypochondria and health anxiety is a brain tumour. So, I think it's kind of ironic that a hypochondriac got a brain tumour. But when these things happen, it's for a reason, and I'm supposed to be talking about this, because I'm still here and I'm okay, and you have to keep pushing through it and fighting through it and finding strength out of your weakness.

00:25:10

But I think psychologically I took the biggest hit, and it created trauma and a PTSD after the diagnosis. I'll never forget the moment I was told that it grew. The world got dark and silent, and it was gut-wrenching. And I think, from there, it created obsessive thoughts, constantly looking in the mirror. Is my eye bigger? Is

it moving the right way? I would feel my eye. Does it feel bigger? And I just couldn't break that cycle, and thinking, did it spread?

So, psychologically, I had a really, really hard time. I still do today. But I had to break that cycle. And I still have to break it every now and then. And episode will come on, and I just tell Karina, tell my mom, tell my boyfriend, hey, it's happening again. And the most important thing is, you have to talk about it.

That's why Karina and I are so passionate about our page, ONG Awareness. That's why we want to advocate for the hidden disabilities with the Sunflower. We have to talk about it because when you feel isolated, your mind's just going to go dark, it's just going to go down the drain. And I finally got out of that shell. Karina got out of her shell. And we were like, we can make a choice. We could either be in the dark, isolate yourself, and go through it, and it's painful, and you're suffering, but you could suffer but make something good out of it and find others that are going through the same thing as you.

00:26:40

So, psychologically, you just have to keep breaking that cycle, and I'm in therapy today about it. And I also took off of work. I took off about three months. I was going for radiation every day, Monday through Friday, so I took off of work. And going back into work, it was a transition, but you can't let these things affect your social life and your career. What doesn't kill you makes you stronger, and it's true.

CB

It's interesting, isn't it, to have lived with the generalised anxiety disorder, but it's something as seismic, as you say, being diagnosed with a tumour that's helped you get on top of the symptoms of the anxiety. Although, obviously, it's something that hasn't completely gone, but you've got coping mechanisms and you're in a much better place with that. And with your work, were you able to go back to the same employer, or did you have to find a new employer?

MC

No, my employer was very, very flexible. I told them everything about it, and I went on leave, medical leave, and they accepted me right back into my job. I'm in cybersecurity. I do IT work. I work from home. So, it was very flexible for me, and I'm very grateful for my job.

CB

Yes, having that flexibility to take the additional stress and pressure off of what you're trying to contend with, with your health, must be a great comfort to you both.

LS

Anyways, yes, so, we wanted to know, how did you learn about the Sunflower, and how do you feel about it?

00:28:29

KS

So, I feel great about it. I'm biased because I have a tattoo of a sunflower, and that was before I realised what it meant. I got it six years ago. But the way I found out about the Sunflower was when I was coming out of my shell and I was owning what I had, and I wanted to get more resources or that comfort and support. I started reaching out to different podcast stations and podcast hosts, and I wanted to share my story, and I came across Holly on the Sunflower page. And she said, you seem like someone who would benefit from us, and we would benefit from you, so let's connect. And that's how I found out about the Sunflower.

LS

Yes, Holly is just fantastic. She really does a great job reaching out to people and finding people that are a good fit for us to speak with. So, I'm really glad that she found you. And Michelle, how did you hear about the Sunflower?

MC

From Karina. She sent me all the information, like, look at this organisation, it's beautiful what they're doing, the mission of the hidden disabilities. It was new to us, and we were going through all the struggles of it, like Karina said, of people looking at you and just saying, there's nothing wrong with you. You're not struggling with anything. You look fine. So, just having that Sunflower and knowing that it's there and that we can advocate and do anything that can help push this mission, it makes us feel really good and honoured.

LS

That's great. Well, we are so happy to have both of you supporting the Sunflower because, as we continue to create awareness, having it better known in Florida will help you. We do have it at the airport now in Miami, and I know Fort Lauderdale has really taken it under their wing and has really tried to expand it as a city. So, hopefully we'll get there with everyone else.

00:30:34

KS

I have seen it in the airport, and I take a picture by it every time because I'm so happy and honoured to be a part of it. The reason that I'm so happy I found that the Sunflower's doing what it's doing is because I was travelling alone often, and I was preboarding, and I would get pushed and shoved, and dirty looks, and everything. And I was like, that just makes you feel so crappy as a person. And I

was like, what do I do to let people know I belong to be here? And when I came across the Sunflower, I wear my bracelet or my lanyard whenever I go, because I know it's slowly but surely becoming more recognised here, as it should.

CB

Do either of you use other aids, walking aids? A white cane, or anything like that?

KS

I have a walking cane, like a stick that people who are blind typically use, just because I didn't know how this would affect me quickly. Because I lost that vision so quick after the surgery, I got so scared, and I bought it just in case. I was also looking for a guide dog I'll probably invest in, because we don't know how this will look when we're older. I haven't been public about this, but I got diagnosed with cataracts in my good eye shortly after being diagnosed with this. So, I don't know what my vision's going to look like soon.

Granted there's surgery for the cataracts, but it just goes to show that anything can happen so quick, and so I do have one. I do bring it with me if I'm going to a theme park or a big crowded area if I'm not with a group of people because I can't see on my right side, so I do bump into people and things. So, yes, I do have that aid for myself.

00:32:25

CB

And we did mention earlier, but I don't think we got into it too much, is that it's young children typically, there's a gene, isn't there, who develop this, but neither of you two have the gene, do you? Is it called NF1?

MC

Yes, it's called NF1, and that's the first thing that we got tested for. We did a whole cancer genetic testing with the swab from our mouth or saliva, and I think both of us, we came negative for everything.

CB

So, when you have children, this is not going to pass down to them.

MC

Correct, thank God, it is not carried down. So, it didn't come back positive, which is good, but then it left the doctors... We don't really know what to do.

CB

Wondering.

MC

Yes. So, I try not to go many places alone.

CB

So, for anybody else who's listening, because I think there must be a few more people outside you two in the world, if they're having a similar experience and probably feeling like you did, isolated, lonely, scared, big decisions to make with not really anybody to refer to, how can they connect with you?

00:33:40

MC

Mostly our Instagram is the best way, ONG Awareness, [ong.awareness](https://www.instagram.com/ongawareness). Same for the TikTok that we're working on starting up. And we want to make this platform available for people to also share their stories. So, if they have not just an optic nerve glioma, but eye conditions, brain tumours. Because even though it's a different condition, it's the same feeling. It's that same feeling of isolation, not knowing what to do, not knowing which treatment. And when you first talk to someone that is going through something similar, it's so much relief. So, our Instagram, [ong.awareness](https://www.instagram.com/ongawareness). And we have an email, as well.

KS

Yes. It's ong.aware@gmail.com.

CB

If you send those to me, I'll include them in the show notes, as well.

MC

Yes, so, we encourage anyone to reach out to us. Doesn't matter. We don't discriminate. We just want to have a community where everyone can be there for each other.

CB

And I guess, finally, are there any positives that have arisen from your healthcare journey so far that you would like to share? Or have there been none? How do you both feel about that?

MC

Okay, so, for me, I would say more positives than anything. It's all about your mindset and how you want to have your outlook on this. Like I said, you can make two choices. You can look at it a bad way and keep going down that, or you can look at it in a positive way, what can I make good out of this? So, that's when Karina and I put our brains together and just said, we have to create

something for anyone who is struggling. So, I think what we're creating right now is going to be very impactful to anyone going through what we felt.

00:35:36

Just another positive thing for me, of course, I found Karina. And she's my best friend now, and we will be best friends for life from this. I also got back into my faith, which is a huge thing that got me through radiation and every day gets me through, my faith. So, I'm very grateful for God and my family. We've gotten closer. These things, they bring you so much closer with your family. I'm an only child, so my mom took me to radiation every day. My boyfriend was by my side the whole time. So, a lot of good things to come out of this. It's still a struggle, but it's much more positive than negative, the outcome.

CB

Yes. And quite clearly, it's the people around you that are enabling you to have this feeling and to do the positive things that you're doing with Karina.

MC

Absolutely.

CB

It's that strong, supportive network which Karina didn't have with her first set of friends, not all of them, but some of them, but now you've found your people. And for you, Karina, do you have any positives that you would like to share?

KS

Yes, I would just echo Michelle and also just highlight that the negatives are always going to suck for everyone. Like, it always sucks to have some negative news. So, that's always going to happen in life. And when you realise that and accept that, I think it makes it a little easier to navigate.

00:37:03

But also, I think that the wisdom I've gained from just the situations I've been in, the decisions I've had to make at such a young age, I'm very grateful for that. At my young age, I feel very wise, and only God could've aligned that for me. And I feel chosen. I feel great. I feel very called to be in this space. At first, I didn't know why I chose to be in therapy, to be a therapist. I didn't know why I chose to be in social work. I thought I knew. But when I had this diagnosis, I knew, and I finally felt called and ready to go. So, I'm happy we're doing this, and that's a real big positive for me.

CB

Well, I just want to say thank you so much for your time. We will look forward to sharing this in the UK and the US, Canada, Ireland. So, try and reach out to lots of different countries, where hopefully there might be some other people who are just looking to connect.

MC

Thank you so much.

KS

So much.

MC

Let us know what else we can do for you guys, as well.

LS

Okay, thank you very much. I appreciate that.

CB

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner. If you enjoyed this podcast, please share it, leave a rating and review to help raise awareness of non-visible disabilities and the Hidden Disabilities Sunflower. You can also follow and subscribe to The Sunflower Conversations podcast.

VO

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