

Transcription for: "01 proof CT 1.1-1.mp3" (Uploaded File) (New Transcription)

The following program is presented with support from CSL Behring, Takeda, and Grifols.

Hello, and welcome to chronic twenties. A podcast from the Immune Deficiency Foundation, which explores living with a rare disease and early adulthood. In this two part pilot episode, two members of the immune deficiency foundations used advisory committee, Cassie Mummert, and Victoria Medal, discuss mental health coping strategies, dirtuality and the complications and joys of dating other people with rare diseases. Content warning. This podcast features sensitive subject matter such as mental health, bullying, religion, suicide, and confronting mortality.

The views expressed in this podcast do not necessarily reflect the views of the immune deficiency foundation, its employees, sponsors, or board of trustees. Listener discretion is advised.

Victoria: I think at Cassie and I I mean, I can't speak for Cassie, but our attitudes going into a relationship with someone who has a chronic illness, we have this sort of mutual understanding of, you know, all the hardships and possible outcomes that having an illness has, we're able to really, like, truly in its core, understand each other. And I feel like that's not very common. It's something that Jesse and I both really cherish and we're both very vocal about how we're feeling and, you know, what's going on with us. And we never hold this sort of resentment towards each other if we're not feeling well and if we can't physically have time to spend with each other even if that be over the phone. So it's this incredibly deep bond that we have that is very uncommon, I guess, in other aspects.

I mean, even people in your own family or friends, for example, may not understand your illness or understand your hardships in the same way that your partner does if he's going through the same thing that you are. So it's just incredibly special bond that we have, not to say that us both having chronic illnesses is not difficult, it is incredibly difficult, and we also go into it acknowledging the bad things that can happen. You have to go into a relationship with the knowledge that you know, something bad could happen to either one of you and you have to understand the grief that can come along with that and how you will bounce back if something does happen to either one of you. And that's not a thing that a lot of people understand or have to acknowledge even if you're healthy. It's not something that you really think about.

But for us, it's something that we can't take for granted. The time that we have with each other, we can't take it for granted. And I think that makes it even more special and especially being long distance too when we already don't get a great amount of time and to spend with each other. It makes the time that we spend with each other even more impactful and more special, and it just confirms that, you know, this person is the one for

you. So it is heartbreakingly beautiful to have a partner who understands and has an illness, but it's at the same time absolutely absolutely devastating because you don't want anyone else going through the same thing that you're going through.

So that's a little bit of my perspective on in case.

Cassie: What you said heartbreakingly beautiful. I think I should be the title of this just saying, I think that sounds great. That's really cool. No. I I think you've pretty much summed up how I feel as well.

I mean, because not only are we dating someone with very similar illnesses to ourselves, but also being in long distance. I feel like those are two not necessarily cons, but and, like, bad things necessarily, but struggles in itself independently. And then when you put them together, it's just like like, I don't know. It seems like I I never thought I would date or be with someone who had health issues. I always kind of whenever I thought about my future, I always saw myself with someone who was healthy that could take care of me when I was sick or when I'm down.

I wouldn't change that for the world that I'm with Ethan. He absolutely takes care of me whenever we are together, like in person, and he takes care of me in every way that he can right now when we're apart. And so it's really I don't know. It's really nice. There's a lot of things that him and I joke about that I said I would never do, that I'm currently doing.

Like I said, I would never date someone younger than me. He is, like, all year and some younger than me. That's very funny. You I to throw that at me a lot. So I don't know.

I just think that's, like, kind of funny in it all. But overall, it is very, I think, stressful not being able to see them every day or check-in, like, I guess, as much as you could if you work together, especially with having health issues, like, you know, on top of it. But Ethan and I try to, like, you said, like, you, like, try to communicate. We're really good, I think, with our communicating and being able to tell each other what we're feeling, how we're feeling, and being open, We also actually, I know we'll probably talk about this later, but Ethan and I do the grape journal together. So I have the grape journal in person here, and him and I both like, do entries in my book every day.

I'll ask him, like, what were what was a positive about today? Or what encouraged you? You know, things the words are great. Like and so here, we'll talk, and then I'll write him down.

And then also he kinda added a fun thing to it.

He says, like, goals for either tomorrow or goals for just, like, a week or doesn't really have a timeline. I guess we're trying to stamp on it, but he does talk, like, about the goals that he wants to accomplish, and it's not necessarily, like, physical. It could also be, like, your mental or emotional goals as well or where you want to see yourself. So I thought that was a really cool touch that he added. Mhmm.

I don't know. I think I think too, I've become a lot, like, I guess, mentally and emotionally

stronger than I used to be by being in a relationship with someone who also has a lot of health issues. I think there's a lot of us that goes into relationships anyway. And it's just like you trust that person to be open and honest. I think more so than a normal relationship or normal and air quotes is what is normal, but, I guess, a healthier person wise relationship and, like, illness wise.

Because like I said, you can't see them. Like, in person, you can't physically see how they're doing. So you're just going by text or phone call. Ethan, I'm gonna try to FaceTime, you know, once or twice every day if we can. There's times where neither of us really feel bad. And to piggyback what Vicki said, neither of us hold resentment towards the other. If we don't feel up to face timing, we both are pretty honest and open and just respect one another enough to know, like, hey, it's, you know, like, yes, you're feeling bad and like, for instance, like, there is just a day or night, I guess, where I really wanted to talk to Ethan. But that wasn't a good time again, being in the hospital at the time. His nurse was in or something. And so he was, like, hey, I can't talk right now.

We'll just have to do my normal FaceTime. At first, I was kind of upset because I was, like, oh, I just really missed you and I won't talk to you, but, like, it's whatever. Like, it's all good. And then, like, I was kinda hurt at the beginning, and then I took a step back and was like, well, no, that's not really fair for you to feel like that necessarily. Like, he's also struggling and, you know, so it's like, you do have your moments, but you're able to bounce back pretty quickly.

I feel especially talking to them. And being open and honest.

Victoria: I think it definitely helps to being in a relationship with a person that you trust so deeply because you know that they value your time and their they only have your best interests at heart. So you never have that sort of, like, guilt or what's a blame that you put on the other person too because of it. And I know you hadn't talked about your grape journal, and I actually wanted to ask you a bit about that because I know it's been a almost like a lighthouse for you. It's gotten you out of some really, really difficult times, especially when you were just diagnosed too. And also, I know that you mentioned you recently got baptized.

Because I I got baptized too in May and I found for me personally drawing closer in my faith and in my relationship to god has improve my mental health quite drastically. So I guess if you wanna talk about your grape journal and your journey with faith, I would love to hear more about it.

Cassie: Yeah. So my grape journal, I started well, I guess my mom technically started it. I just used it. But she helped me I was in a really dark place after getting diagnosed. And I think I was on treatment.

I was on IVIG at the time for about, I think, a month or two. And I had a really hard

appointment where I wasn't feeling good from one of them. And we were driving. It was, like, an hour and a half for two hour drive home. I forget what it was, but a long drive. And she she I had my music playing and she asked me, like, what's your favorite color? And I just remember looking at her, like, in a passenger seat, like, No. We're like, you already know my favorite color. We are not doing this. I had to preface this. I was like fifteen, fourteen, fifteen. So, you know, I was kind of your movie teenage girl just a little bit, but then also being on steroids. This the word word range is real.

Victoria: But is

Cassie: Yeah. So you can imagine. I was I was kinda mouthy, but I think she forgives me, hopefully. Uh-huh. But I just kinda I don't know.

I'm looking at her, like, no. We're not doing this. Like, you know my favorite color? And she's like, no. What's your favorite color?

I was like purple. And she's like, okay. What's something that's purple. And I was like, why are you asking me this? This is pointless.

Like, I just want to listen to my music. And she's like, no. What's like, what's something that's purple? And I was like, grapes. And she goes, okay.

And this whole conversation took the whole ride home, like, literally, the whole hour and a half to two hours because I'm pretty sure there was traffic that day. It felt like an eternity, to be honest. But she we came up with grape, and it's I had to come up with a positive word for each letter grape. And so it's grateful rewarding attitude. Positive and encouraging.

And then when we got home, she took a composition notebook and put, like, purple scrapbook paper, just, like, cardstock paper on the front. And wrote grape and wrote the grape words and decorated it with purple stickers and she made me a grape beaded bracelet that was just all purple beads and spelled grape on it. And she gave it to me and she had made her cell phone too. And that night, she sat down with me and she said, okay. We're gonna turn.

And I was like, oh, boy. What did I do? Right. Exactly. Oh, and so I was like, okay.

And she said, okay. We're great. We're gonna come up with three things that were positive end of the day. And I was like, okay. And she's like, it has to pertain to your five.

Positive works. I was like, okay. I was like, at first, I was kinda like, well, this is gonna be easy. Not really. It's not very easy, especially when it was like hard days all the time.

I thought it was gonna be easy. I like to believe it was that it wasn't. And for the days that you got, your positive entries, then she had this vase for us and, well, each vase for, like, each vase. She had two. And we had purple light glass beads and then we had clear glass beads or a different color.

And for every positive entry that we did, if you got three positive entries, you put three purple's in. But on some days, I could only find one or two positives, and then I left the

other, like, one or two spots blank. Then you would add a clear or different colored bead to the vase. And so over time, as you're doing your entries, you can see how many good days you had over that. And so when we stop the vase thing, after a little bit because the vases got full and you don't really have anywhere to put the beads and, you know, but it was nice. I kept I think I kept a full jar just to see that there was still, you know, positives in every day than when it was a bad day. And I got to see how far I'd come. Like, I think it was, like, over a year or something that the vase kept. But I still do the grape journal. Like, nowadays, I've had to, I think, make myself another two or three since then.

A good handle, but and I just recently at the Chicago teen escape, I got to make a whole bunch and hand them out with beaded bracelets. Let's say, great. And got to, like, share that with others. And that was really rewarding for me because it was, like, I never thought it could be something as cool. Oh, that's awesome.

I never thought it could be something, like, as cool and as like I don't know big as it is now. I didn't think it was really something that, like, I wanted to share. I mean, I've been involved in IDF since twenty fifteen. So the whole time I've been involved, I've been using and doing my grape journal, but I never got to talk about it until just recently. But I'm very grateful that I did and I'm very grateful how do you have made me the opportunity to share it with others and speak about it.

And I'm excited to see, like so who all it can, like, reach and help. I know it was super helpful for me and super like. Just I think it showed where even though it was like dark, there was still light, which was really cool. And that was something that, like, I needed back then. Which was, like and two, I think it helped with me remembering, like because I don't remember the bad stuff.

All I remember now when I look back is what I wrote in the grape journal. And I there's, like, three that I could tell you the stories about that that's for another day, but they were very cool that I I don't think I would have remembered or even, like, thought too much about if I didn't have the grape journal to think about and be, like, look for positives in the day. So I'm very grateful that, like, I have those memories and that experience too. So really, really beautiful thing that

Victoria: that you've done. I was so so happy to see your grape journal at the conference and your little great great swits as well. I think that they are helping so many patients and kids who are struggling with their health journey. And I know I mean, it's helping me now, but I know little Vicky, like, fourteen, well, not so little, I guess, but little little learn that you really would have liked to have something like that. So I think it's it's really beautiful.

Cassie: Mhmm. Thank you. Yeah. Of course. Alright.

Victoria: And how has your journey with Faith's been?

Cassie: Yes. So I got baptized on June twenty first. Actually, I have at his shirt that I got that day. It says, I have decided to follow Jesus. And it was really cool.

I thought that ties with another whole family. I think there was, like, seven of them. And so I was kind of the the odd one out. But they welcomed me and kind of accepted me in their family. I think I was actually in their family photo that they took.

They're like, come on, let's just all get together and they still just put their arms around me like, here, get in the photo. That's kind of fun. But I I've been a Christian, I think, like, since I was a little, I remember going to church when I was, like, elementary and everything. And then probably about the time when my mom started my grape journal, I I think I lost my my my faith a little bit, made some, you know, questionable decisions here and there. Not like bad, bad, but enough to make you like.

Yeah. That that wasn't good. Like that. Looking back, that's not who I wanted to be. It was, you know, just a rough time.

And I think everyone makes mistakes, obviously, no one is perfect. And so there is a lot to learn back then. And I wish I knew what I knew now, but it's so good. That's life. But I we've just started going back to church in February.

During COVID, we did, like, online church and we watched some pastors online and, like, it was cool. And they had a church that we could have gone to, but we weren't once, and it was just not the church for us. We were, like, okay. And then we just recently started going to this new church in February, and it's been awesome. Like I said, I got baptized June twenty first, and I was probably the actual best decision I could have ever made.

I I it's cliché as it sounds like truly feel like a different person from that day on. I feel happier.

I feel like clear in the head. I still have my bad days for sure. I still have my depression, for sure, and my anxiety, but it no longer has this dark hold on me like I used to let it.

I do bible studies with my mom. I do a bible study with Ethan, and then obviously going to church, you learn more and more about the bible in in a different way than what you would if you just read it alone. And so that's been really cool to do, like, all three differently, but you're still learning, you know, who God is, and that's been really helpful for me. I actually joined what they call the dream team. And it's where you serve in the church.

And so I was on the worship team that that didn't work out due to, like, pain and stuff. I'm not able to stand and it's just not the right timing, not the right thing for me to do right now. But I am able to work in the nursery there, which is my absolute favorite thing with the lawn and the nursery and with the toddlers, absolutely a door kids. So that's been really cool for me to do. I served, like, once or twice a month.

They never do it back to back Sundays because they don't want you to get burned out. But that's always really, like, cool for me to wake up and be like, oh, yeah. I get to serve today.

I'm like, I gotta go hang out with babies and toddlers. So, like, it's fun.

And it's fun to see them, like, how they learn the stories that you're teaching them. So, and,

like, how they interpret things. And when they were in bible verses, especially the toddlers. They're cute when they were in those. But yeah.

It's it's surely been life changing. Like I said, I do feel clear. I feel happier. It's easier for me to see the positives, I feel. And I'm learning like, I've always known everything happens for a reason, but what we as like, what we think is our plan is never really our plan.

It's always God's plan and God's timing. And that's what I'm reminding myself with Ethan's situation as well. It's like even though it doesn't seem like this is not what is supposed to be happening None of us wish it were happening, but ultimately, like, you know, it is in God's hands and he is the ultimate healer. So I just have to remind myself that mainly. Yes.

Victoria: Yeah, I know for me it was a really transformative experience to realize who God was and why Jesus died for us. And it just really makes your whole life and all the things that you've gone through, everything that you've suffered with, almost worthwhile, because you know that you know, this is not all that there is to your life and there is beauty, there is surrenderance there is, like, so much that we can look forward to not only in life but after. But I know when I was growing up and when I was still struggling a lot with infections and whatever the heck else I had to go on. Just three still don't know. But it was really, really easy easy for me to drown myself in work.

I had this really, really bad habit of just locking myself in my room and not coming out, not eating or drinking, and just you know, taking your mind off of the pain and off of the illness, by keeping your mind busy with with other things. And honestly, it doesn't sound like a really terrible thing to drown yourself in work, especially if you're going to procrastinate or something like that. But it was a very maladaptive thing because that also didn't help my health. I mean, I was getting sick constantly because I wouldn't eat very much and I couldn't eat very much, I would also drift away. And it became like this sort of cycle of I am not helping my case whatsoever, and I kind of feel sorry for myself, but I don't know how to stop.

So I guess that was one mal adapted behavior. I didn't really have any other outlet besides school. And then when I couldn't even be in school, it was like, oh, what do I do now? I don't know. And I had taken actually hiatus from piano lessons too because I was so sick. And so I started piano lessons back up again. I I was like, right, before I went to high school and that helped me tremendously. It was like, as if as soon as I sat down at the piano, all of my problems disappeared even if my my siblings were, like, running rampant or they were screaming upstairs, Like, I just was un bothered by it. I just didn't care because I would just sit down and I would play and I would lose myself in the piece that I was learning. And it's something so magical about having music and having an art form to to fall back on because it's a way that you can express yourself and it's a way you can express yourself that's unlike any other way that you can It's almost like you're spilling out your soul when you're playing

music.

So that for me was really a huge thing. And there was also, you know, spending time with my family there would be times where I physically could not spend time with them because I live with my grandmother and grandmother started to take care of her and my family is down the street. So, I mean, it's not like we're far away from each other. But the thing was if I got sick or anyone was sick at home, no. No.

You can't. You are not allowed to go home. You've been banned. So And that happened a lot, especially during cold and flu season. So I would be kind of secluded from my family at home.

But also a big thing was that helped me get through. All of it was being here with my grandmother and helping take care of her. It kinda gave me another sense of purpose like all of my illnesses and trials are because I can connect better to my grandmother's. Issues and how she's feeling. So in a way, we have this really beautiful interdependence on each other, on one another rather.

Cassie: And

Victoria: I find so much fulfillment in in caring for her. And that's also made me realize that I really want to go into medicine because I want to be able to expand that in any way that I can So all of these, I guess, these little things I mean, some are better ways to cope than others, of course. But they all made me kinda realize that we have a greater plan. Our suffering is not worthless, although sometimes we feel like it absolutely is and that there's no rhyme or reason to any of it. But it's it's really reminiscent of, you know, how we can live our lives to have meaning, to have purpose despite all of the hardships we face.

So, yeah, that's been a that's kind of been where I am now, too, because I'm still going back and forth between diagnoses and I still don't have answers. So I'm relying on people piano school. God.

Cassie: Yeah.

Victoria: Well, to, you know, get me through, like, please, someone throw me throw me a phone here because this is time. But, you know, that's

Cassie: Well, I'm very glad you have, like, your grandma that you can take care, like, like, not like, I know you should take care of her, but, like, also, she takes care of you in a way, you know, which is so cool to see. And I think it's really important to have, like, a support system and a good support system as well. Like, I think coping mechanisms are definitely great and very helpful and useful. Mhmm. But I think that they can order so far.

And if you don't have support of people in your life, I don't think you're ever truly going to get where you want. And it doesn't have to be like family members either. I know plenty of

people outside of family that I could call on if I needed. Now my family is absolutely great. They're my number one support system, but some people don't don't have the family side of it, or they do and their family doesn't exactly.

Believe or think that they're as sick as they are. I know a few of my friends have had that, like, friends with health issues and stuff. I've had that. And it's really hard to see And also they, like, be there for them because I'm, like, I I have something wrong with me, like, mental wise, physical wise, like, health wise, even just your everyday, like, Some days, I'm just like, I'm sad. Like, I just need a hug.

I'll just go to my mom and be like, can I have a hug? Like, I'm sad. I feel good to call you, of course. And then, like, when you talk to your friends that maybe you don't have that, And they were like, I'm like, well, can't you, like, ask your mom? Like, can't you go to your mom about this?

And they're like, no. I don't like. And so it definitely puts it into perspective Mhmm. Because it's like, if you don't have support of people, I think that does take a toll on your mental health because then you start second guessing for yourself or you don't feel like people believe you, you don't feel like It's real. Like, I'm I'm I don't know.

I can't relate to those emotions, but I definitely know people who who have and who have felt that and I can be there for them the best I can. And so I don't know. I think, like, if you have a friend, pets are always good. Sometimes you don't need people to talk back. All you didn't answer.

All you need is to be able to get it out. Unless you have a dog like me. I have a little rat terrier Jack Russell makes Romeo who was barking up previously. He likes to give his two cents often. He also doesn't say the nicest words, which is bad.

But but no, I think I think anyone that you could call on to be there for you, I think, would really help. And I'm super like I said, I'm super grateful for my support system, my family, Ethan, his family. I have, like I said, friends, Vicky, my fellow Yac members. And yeah. Kat, Josh.

Zach? Yeah. The whole nine yards. I could go on. It's like you're receiving an award and you have here, thank you.

It's listed out. But no. I do I do think the support system is big. It's a big one too. So and two, I like what you said earlier about having art and being able to express yourself.

And like you said, kinda sharing your soul or expressing your soul. I don't remember exactly how you worded it. But I thought I was very cool. Art is big for me. I like to doodle.

I don't I used to I was in art class in high school. I used to, like, actually sketch sketch and do, like, full on art, like, drawings and paintings and stuff. And now that I have a lot of, like, arthritis, I actually just got diagnosed with non rheumatoid rheumatoid arthritis. So it's like make that make sense. But it's basically joint pain that mimics rheumatoid arthritis, but is not rheumatoid arthritis.

And like the rheumatoid arthritis meds, won't necessarily help this. I just started doing that, and I can't tell if it's working yet or not because it's just a few weeks in. And they said it could take three months for it to kick in full because that's the build up over time. But because of my joint pain and stuff, I can't really hold a pencil like I used to, and I can't move my wrist and things, like, you know, as easily and as fluidly as I used to. So now I just do what I call stupid doodles.

I put air quotes around that. And my goal is to one day turn those into stickers and sell them because they're just they're fine. They're cute. I drew a recently, I drew a little UFO looking thing with alien in it, and then it there's a, like, a just a shadow, like, silhouette of a person that says see you later. Like, you like, got the got the, like, beam coming down to pick them up?

Victoria: One of them right now.

Cassie: Yeah. I wish. I wish I could crank them out like that. I can't wait until I can, but and my goal is to do stickers for my grip journals, like design my own and do that, and then I can decorate them however I want with my own stickers. So that'd be cool.

Victoria: I have a kind of heavy question if you don't mind. Okay. And I know you're also going through a heavy time. Because you lost someone who was, you know, dear to you. Mhmm.

You had any fears about your future? Like, what it entails?

Cassie: That's a very good question. I think about my future a lot, actually. It's not at all what I thought it would be back when I was younger. I think your future changes anyway. But yeah.

It it was definitely out of the blue. I lost a very good friend last month. Kinda trigger warning, I guess. But it was suicide. They they were being bullied.

They had a lot of survivor skills. They had just a lot of a lot of things going on that I don't think too many people knew about. They were a very outgoing, very fun they were they were just a really good person. Mhmm. And I'm very grateful for the time that we, like, got to talk and got to hang out and stuff.

They also had a PI like us. I had actually met them at IDF, and so I mentored them for a while. And so it was tough hearing that news and realizing that, like, you won't see them anymore. Like, you won't necessarily get to have the conversations that you did. And so and I think about them, like and what their future I would have looked like.

Like, I know what they wanted to do. Mental health was super important to them. They advocated a lot for mental health. They advocated a lot for PI. That was very big to them. And so I I guess in one way that I want to give back to them is to honor them with, like, talking about mental health and advocating for that. And like, I guess, just being there for

others better in a way. And so when I think about, like, my future in that way, that is one thing that I want to really focus on is, like, really checking in with people. And when they say that they're okay, like, if I know, forget the sense that they aren't okay, not to push or to cry, because I don't think that's necessarily the way to go about it, but check-in more often.

Maybe don't even just be like, hey, how are you?

Just, like, send a funny joke or a meme or, like, if you think of them out during the day, like, send them a picture of something that makes you think of them. Like, it doesn't always have to be like, how are you? Honestly, when people ask me how I am a lot nowadays, it's like, you're just asking me to make small talk. You don't really care. So I say, I'm great.

Thank you. How are you? And I'm very good at faking that as I can imagine, a whole bunch of other people are. And so I think if if we were able to kind of switch it from, are you okay or how are you or you know, questions like that and just being like, hey, I saw this and thought of you. Or, like, recently, just, like, I guess, give an example, Ethan's mom.

She went for a walk around the NIH. Campus. And of course, my favorite colors purple. She found these real pretty purple. I think they're asters, the flower, and sent a picture to me and said, I thought of you because they're like Cassie flowers.

And I don't think she knows this, but Asters are one of my favorite flowers. So that was that was really cool. And I was like, that made my day. And she's like, oh, it was just a small picture or like a quick picture or something like that. And I was like, yeah.

But that meant more than you know. Like, honestly. And, like, when people text me out of the blue and ask me, like, if I'm gonna be at craft class or because I do a craft class on Thursday nights. Well, it's one Thursday in a month. You go, like, every third Thursday or something.

I'm like, they're like, hey, are you gonna make it to craft class? And then I'm like, oh, like, I am, like, wanted or needed or thought about. And that I think if I think, I guess, checking checking in on people like that. I think maybe help. So that's what I really try to work on now is to the people like when I reach out, not necessarily ask how are you because I think in nowadays, you just kinda get a fake answer anyway.

So it's just like small talk. No one actually really, you know. But I think I think yeah. I think just trying my best to be there for others and, like, reaching out better and really advocating for mental health and bringing awareness to it. I think is how I want to.

Like, it's not better in my future, but better in my future when I think about it.

Victoria: That's really beautiful. That's the super important. And I think we're very fortunate to live in a time where mental health is being talked about more and it's not as much of a taboo topic as it was a couple of years ago, even decades ago. But, yeah, it's it puts a lot of things into perspective, especially if you're I mean, with a chronic illness and you kind of have to deal with issues of mortality anyways. Yeah.

It can be incredibly taxing. Because we we have to think about things that other people don't have to think about at all or it doesn't even cross their minds. I think I know I'd this a little bit in the documentary, but being, like, especially not having any sort of diagnosis. I have a little bit more direction than I did a couple months ago, but having everything be up in the air and still feeling quite terrible and just trying to push push through is so exhausted. It's and it makes you think because you don't wanna get stuck in the cycle of, oh, I can't do this or I can't fulfill my potential because I'm sick.

Or because I feel this way. But at the same time, you also have to acknowledge your personal limitations, what your body can handle. And I guess that trying to figure that out, like, where the intersection of those two ideas meet has been incredibly difficult for me because I've always been the type of person to just do everything for everybody and then put myself absolutely last. I think you are that way too. So

Cassie: Yeah. I I completely feel you on that.

Victoria: Yeah. So it's just trying to figure that out has been incredibly difficult. Because next year, I'll be applying to medical school.

Cassie: That's exciting.

Victoria: Sure. It's exciting. But, Tesh,

Cassie: I'm sharing.

Victoria: It's all now, like, the existential dread is hitting me. I'm like, oh my gosh. It because of the rest of my life we're talking about, and it's incredibly exciting of something I've wanted for so long. And then that little voice in the back of my mind is telling me that, oh, something something is bad is going to happen to you or you're not going to hand you're not going to be able to handle it physically. And that really gets me into a spiral mentally. Because I just I don't want to have to live and have this to be a constant plague on my mind. It's terrible. It's a terrible way to live.

Cassie: So what do you do when you have those thoughts? Like, how do you work through it?

Victoria: Well, I try to, you know, obviously, I talk to my family and I talk to you, well, you're my family too. But I'll add family. I talk to Jesse and talk to, you know, anyone who's part of my support system, my my close friends too. And it helps. And I I think also, like, being into faith has also helped me bring bring bring me out of that, like, loop in that cycle. But, I mean, I still have bad days just like everyone, especially in the days that I'm feeling so bad. And like for example, there was a day this week where I I frequently have to wake up at, like, five thirty to six AM for school and then I'm at school until six:thirty at night. So I get

home and I'm absolutely exhausted. And I still have a mountain of work to do. And on top of that, I have to go shopping for groceries.

And on top of that, I have to make sure that my grandma's okay and taken care of, which is a privilege. Don't get me wrong, but it's just it's so much to think about and it becomes such I don't wanna say burden because it's not a burden, but I'm likening it that way because of just how much it weighs on you. Yeah.

Cassie: That makes sense.

Victoria: Yeah. So I wake up And then, you know, this particular day, I just would not get out of bed. My joints were acting up. My stomach was bothering me. I had a terrible migraine. And I'm like, oh, gosh. Because I've been having more of those days recently. And it's just then I start to thank my Victoria. If you can't handle this now, you know, how are you going to do this in medical school? How are you going to do this?

You know, when you get married and have kids and, you know, have people that depend on you to, you know, perform your best at all times. It's a lot. And I think especially if you want to go into any sort of field like that or healthcare in general. And you have some sort of chronic illness going on and we have other responsibilities. It's just a lot of things that you have to take into consideration when you're planning out your life.

But then as we know, life does not go to plan ninety five percent of the time. So yeah. Like, you can make all these grand plans for yourself. And, you know, having something to look forward to is amazing. But that is not the reality situation and especially not the reality if you have chronic illness because so much of it is just unexpected, unpredictable, it can take you out for days out of time, even weeks, you can be in the hospital, you can even be on that store at any given moment, and you don't know when that will be.

So all you can do is just live to the best of your ability, live with that, live with purpose, and just live like, you know, you are going to die at the ripe old age, about ninety. And you're gonna look back on your life, but absolutely no regrets surrounded by family, people you love, I mean, I think that's all we can we can really do because getting into the mindset of you won't be able to accomplish something because you have these limitations is just is quite maladaptive. But, you know, at the same time, you'll also have to realistically look at your situation. Yeah. And especially when you when you tie so much of your identity into what you want to accomplish.

So if you don't accomplish these things in a way you feel like a failure.

Cassie: Yeah. And you feel like you're not who you were supposed to be too. I feel like

Victoria: Yeah. I feel you know, we just have these existential thoughts. It's like, their people actually think this way or am I just crazy?

Cassie: No. You're not crazy. Well, if you're crazy, then I think me and, like, seven others that I know of are crazy. Yeah. But no.

No. I completely understand how you're feeling or how you felt. And I get that that I actually wanted to my first goal, my first, like, dream job is in, like, my future when I thought about it in high school was that's going to be an art therapist because I absolutely love art. I love I love kids and I love this is gonna sound really weird. I love old people.

Like, when Right. Like, no. Yeah. Like, my great grandma, she just passed away in May of last year from Alzheimer's. And she had been in the nursing home for I think like thirteen or fourteen years with it and she suffered another eight years at home before I put her in there just with Alzheimer's.

But and I would go out there and I would do crafts with her and her unit And a lot of times the art therapist there would be like, hey, if you have an idea, I'll get the stuff, you tell me I'll get the stuff and we'll you can teach it. And I was like, really? And she's like, yeah. And so a lot of times I would actually do the art therapy there. It gave me something to do.

I was home bound from school, so sure, why not? And so I got to do that. And so that kinda what led me to it. And then I wanted to go to nursing homes and do it. And, like, be like a traveling art therapist if that was even a thing.

I don't know if that was my goal. Mhmm. I wanted to travel to different hospitals and go up to the, like, the pediatric floors and do art therapy with the kids. Because that was something that, like, I really remember when I was little on being hospitalized was the art therapist and just the positive people that always came in smiling and they did stuff with you. They made it fun when it was not fun.

And so that's kind of what I wanted to do for others. But then I realized in the time it would take me to do the the schooling for it, I cannot go full time. I would have to go part time. And even if I did half of the work, like, or half of the what was required. Mhmm.

It would take me twice as long and right there as sixteen years of schooling alone. And I thought if I graduated at eighteen, and you add sixteen years of schooling, and then you have to find a job. Well, probably then you have to enter. And then you have to find a job. At that point, I might as well be at retirement.

Victoria: I couldn't even get it. Oh, because more than medical school and like doctor training.

Cassie: Yeah. Because you have to go for art classes Yeah. Which are hard on themselves because they say for however many hours you put into your art piece, your artwork in class, you have to do double that outside of class. Well, first of all, that's just not possible.

Victoria: Like, who don't know?

Cassie: I love art just as much as, like, next person. But, no. That is not how this works. And a lot of the schools that I went to to look at for it were very rude. And we're not accommodating at all.

So I kind of got discouraged. And for a long while, I felt how you said, where you felt like you tied a lot of yourself and your identity to your dreams or goals. And so I was like, if I can't do art and I can't help others, I want no part of this. Like, I'm done. I'm going home.

I'm going to bed. So it well, with me. What what does Ethan say, Pain, despair, and agony? Woe is me? Oh, quote Ethan.

Yeah. So, like, it's it was awful there for a while because I was, like, I can't do anything. Like, if I can't do what I always thought I was gonna do. This is awful.

Victoria: Yeah.

Cassie: And then I had the bright idea, well, let's go to culinary school because I wanted to be a baker, but apparently, you can't just start baking. So it was like, alright. Even though I did, that was that was actually one of my big coping things was I would bake. When I was on IVIG, okay, back story here real quick. When I was on IVIG for, like, four and a half years. Every infusion, I got them every three weeks. Every infusion, I did them at my doctor's office, and then my last year, well, half a year, I guess, I was at a cancer center. But every infusion, I would make bake, I guess, something different for the nurses. Whether that be cupcakes, muffins, new cookies, breads, like friendship breads, zucchini breads, things like that. Different, like, cheese balls with, like, like, like, sweet cheese balls.

Like, you would eat with, like, graham crackers or animal crackers, things like that. I would just come up with half the time I would I would bake with stuff that I couldn't eat. Like, peanut butter and a whole bunch of different stuff just because, like, it wasn't for me anyway just because I can't eat it. There's gonna be somebody else can't. I mean, I know there's people with allergies, but, like, you know.

So I was like, it's fine because then it also deterred me from eating it. Because if I liked it, then I wouldn't give it away. So it's like, well, but but no, I would bake for a while. But I tried culinary schools, that was a vaccine. I tried culinary school.

But with all my food allergies and being airborne allergic to oranges and, like, obviously, the smell of oranges, they were like, well, we can't guarantee that. You can't be here. Well, thanks. So then that went out the drain. So then By then telling me I couldn't be there, even though I had nothing to do with my skill, I immediately stopped baking because that's it.

I'm not good enough. Like, I'm done. Once again, I'm going to bed. I do not care. It's so dark. It's hovered. It is. It is. And it's and it's hard when people tell you know or that you can't do something. Like, normally, that just makes me want to do it that much more, but not when it's something that, like, you really want to do.

Like, you see yourself doing like a goal or a dream. Mhmm. And it's almost like reality

checks. It's like I think it's like god's way of being like, nope. This is not right for you. But like, could you be a little nicer? And sometimes it's like I don't know. It's like, do I wish I would have been in culinary school anyway and just not told them about my allergies? Sure. But then if I had an issue and I knew about it, then it's like, well, you kinda set yourself up for failure anyway.

And then how would they react? Yeah. But I know. Those those are, like, my two main things that I wanted to do. Currently, I'm just kind of at home.

Obviously, volunteering for IDF, which is a huge, like, that I tell people whenever they're like, what do you do? Like, what do you do for a living? I'm like, Oh, nothing. Like, I'm just at home. And my mom's like, you are not just at home.

Yeah. Like and I was like, what do you mean? I'm probably the longest time this is how I was about it. I was just like, well, I am. And she's like, what do you do for IDF?

And I'm like, oh, well then and then when I explain it, the person that, like, we're talking to is like, that's actually really cool and, like, really big. Like, you're doing amazing things. And I'm like, well, really? Like, I get to be there for others. Like, that it more helps me.

And they're like, but look at all the people that you've probably helped. And I never saw it that way for the longest time. I never I never truly saw it as I saw it as helping others and I loved that. That's why I started volunteering and being a mentor to teens, specifically the younger teens because that's where I needed it most and where I wish I could have had that. Most.

And so I think that's why that resonates with me so much working with the younger teens is because it's like I can relate to how they're feeling. And I want to be able to give back to them. How I wish I could have had that. But I never saw it as helping others as like a job. I saw it as something I got to do and I got, like, what I got to do helped me in the long run. Like, whenever we go in person to team escapes or the conferences, it's like, I automatically have this, like, I call it, like, my my battery. My internal battery, and it's like, I am on empty. Like, I am dead. Yeah. And then, like, after Chicago, I was full.

Like, I was like, okay. I'm fully charged. Like, and happy again, people who get it, and then looks like you're driving home and you're like feeling the high and then you come back home and reality sits in and you could start slowly feeling your battery go down and down and down. And it's like, I don't know. It's it's just eye opening to me because, like, I never I never thought me helping someone, like, how I I guess how we are.

I never saw that as a job. I see although now when I see it, like, as my job air quotes around that, like, not a job, but people are like, we don't get paid for that, and it's like, well, no, not in money, but you get paid in so many other ways. And it is so rewarding. To be there for others and, like, the relationships that come with it because, like I mean, if I didn't go to idea, I would have never met Ethan. And that is a big part of my life.

Like, he is obviously probably the one of the greatest things that has ever happened to me,

like, very top. And, like, our relationship, Vicky, and our friendship, and, like, you and Jesse's relationship. Mhmm. And it's it's, like, I guess, you can, like, going back to it, heartbreakingly beautiful because it's you have something so awful. You think it's the end of the world.

You don't know how long you have to live. At any point, you can get sick. And it can turn for the worst as we've all, I think, have had at some point in our life. But in the end, you have at least for me, like, you have idea where it's like it is your light and then it's like what has come out of being bad.

Thank you for listening to chronic twenties from the immune deficiency foundation. This conversation will continue in part two. Your support of the immune deficiency foundation helps make sure people like Cassie and Victoria have the education, resources, and advocacy they deserve. To learn more about the immune agency foundation or to get involved, visit primaryimmune.org/donate.