

How to cope with grief, anxiety, and loss? How to talk to others about my diagnosis?

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[00:00:05] **Dr. Michael Levy:** Next up we have Christa Hutaff-Lee from Children's Hospital in Colorado. And the topic is how to cope with grief, anxiety, and loss. How to talk to others about my diagnosis. Thank you, Christa, for being here.

[00:00:21] **Dr. Christa Hutaff-Lee:** Thank you so much. I really appreciate the opportunity to be here and to speak with everyone today. I'm sorry that I also couldn't be there in-person, but I'm really thankful for this hybrid opportunity. It looks like we have a lot of people joining us from really all over the world, which is just so amazing. I also want to thank Dr. Harder for inviting me and recommending that I was able to be able to present today. So, thank you. I'm going to be talking a little bit about just the first steps after your initial diagnosis. So how do we cope with that roller coaster of emotions that you'll experience after the diagnosis, and then how to talk with other people about the diagnosis.

[00:01:02] So my approach to this presentation has been just some really broad-based ideas to help orient you. Everyone is on their own individual journey, and some of these things may resonate with some people and not apply to others, so recognizing that. But wanting to give you guys some ideas. and then if we have some time, talk a little bit about some ways to start your thinking about your own individual journey on this.

[00:01:27] **Moderator 2:** Christa, can we ask you to please go full screen with your PowerPoint presentation. It looks a little small on our end.

[00:01:36] **Dr. Christa Hutaff-Lee:** Yes. Thank you. How about that?

[00:01:38] **Moderator 2:** Yeah. Awesome. Thank you. This looks great. Thanks.

[00:01:41] **Dr. Christa Hutaff-Lee:** Okay. Absolutely. Thank you. All right. So, my first thing is I just don't have any financial disclosures. I'll talk a little bit about my background. I did undergraduate training at the University of Denver and participated in a lot of different types of research with children at that time, and then did some graduate training at the University of Northern Colorado. I'm formally trained as a school psychologist, so I know a lot about the different types of interventions that many kiddos can get within the school setting.

And then I completed a neuropsychological internship at the Children's Hospital in Colorado, followed by a neuropsychology fellowship at Texas Children's Hospital, Baylor College of Medicine.

[00:02:25] Much like Dr. Harder, I work in a neuroimmunology clinic for children, a multidisciplinary clinic for children with a variety of different demyelinating and autoimmune diseases, was established in 2015. And as a part of that work, we also have monthly evaluations where we complete targeted evaluations for children who come into our clinic. They also get an opportunity to meet with a psychologist, neurologist, social worker really to provide this wraparound support. And then we are involved in research and educational opportunities as well. So today what I want to spend some time is just talking in the initial steps after your diagnosis, things that can help orient you along the path. Some ideas of how you can talk with others, and then some thoughts about how to manage some of the emotions that you may experience on this journey.

[00:03:20] So the first stuff that we'll talk about is just gathering information. So often times talking with your medical team is the first recommendation that we have. Many of them have good resources out there. So, Doctor Google has lots of great ideas, but can sometimes lead us down a spiraling case that we don't want to be on. And so really asking your medical team and being able to connect you with good resources. Some ideas that can help make the most out of your appointment would be to write down some questions before your appointment there, and we've all experienced that white coat syndrome when you go into a session and the physician is talking very quickly, and you might not remember the questions that you had had prior to the appointment.

[00:04:06] A lot of individuals benefit from starting what's called a health care journal. So being able to monitor your symptoms or how you're feeling on different days. And this can really help provide valuable information to your medical team but can also help you start tracking for patterns and potential triggers that could be helping you feel worse or having symptom recurrence and things like that. Bring someone with you to appointments. It's really helpful to have a person who can listen in and be able to review what you heard and provide additional information that you might have missed during the session. And then again that idea of asking for reliable resources for medical team, who would be a good resource or what community advocacy groups are out there that might be available to provide you with some support.

[00:04:58] And being mindful of online resources. There's just so much information out there, but we want to make sure that it's giving you the right information and that you're not unfortunately experiencing misinformation or things like that, that might lead you down a path that would not be as helpful for you. So, this idea of processing emotional response is really important. Whenever you hear information about your health or potentially bad information, there's going to be a rollercoaster of emotions, and giving yourself permission to feel all of those emotions and to not feel guilty about them I think is really important. I think it's very normal to feel angry, or scared or anxious about all of these things, and giving yourself some space to feel those is very valuable. But it's also important in this moment to seek emotional support and that maybe from families, or friends, or potentially from professional support. So, there's a number of support groups or even individual therapy that might be helpful to get some support during these difficult times.

[00:06:10] We talk a lot about developing a support network. So, we often just talked about this emotional support. So, from families, or friends, or from other people that we're stronger together, kind of idea of reaching out to other people who have the same or similar diagnosis, and hearing about their journey and what helped them can be really valuable in this stage. Often times we talk about what physical support. So, this idea of during this really stressful time, can you have some assistance with house chores or with transportation or meal prep? Are there people that you trust in your circle that you can reach out to, who might be able to lighten your load a little bit so that it gives you a little bit more time to recharge and to strengthen yourself during these times? There's also a number of formal accommodations that you can talk about with. The

Department of Vocational Rehab can be one resource for individuals who might need or might want to apply for accommodations within the workplace.

[00:07:14] There's also a number of school-based accommodations or interventions that are available for children and adolescents who might need support within the school environment. So, one of those is a 504 plan that can provide academic accommodations. So, things like preferential seating, or being able to have some extended time, or rest breaks, things like that that we can use to address some of the fatigue or lingering symptoms that children might experience as they re-enter the school system. Some kiddos benefit from more significant academic interventions. So, schools can offer what are called individualized education programs or IEPs where children are offered additional academic instruction or sometimes therapies like physical, occupational or speech language therapies and be able to have some additional support that way throughout the school to help them be more successful.

[00:08:09] Many schools are also offering what's called a multi-tiered system of supports or MTSS program or what used to be called response to intervention or RTI. These are more academic interventions within the general education classroom, and so to help support reading, or writing or math development within the general education classroom and can also be beneficial for some students. Dr. Harder talked a little bit about healthy habits, and so we know things like diet, and exercise, and good sleep can also help support your mood during this time. We'll talk a little bit more about this, but really, determining your values and meaning in this time. So, what brings you joy? What activities do you find rewarding? And using those to strengthen yourself during this time. There's the idea of setting realistic goals. So how much can you realistically complete in a day and what can you say no to? So, some of you may have heard about the spoon theory by Christine Miserandino, and she talks about every day you're allotted a certain number of spoons, and each activity that you engage in might use up one of those spoons.

[00:09:25] And so being able to really think about how much energy you might have in a day and how you want to spend that time and that energy that you have and prioritizing the things that are important to you. And so, you may be a person where family is very important to you, or your career is very important to you, or the volunteer work that you do is very important and being mindful of not over committing. And being able to say no, or at least not right now, to be able to give you an opportunity to focus on the things that are really important to you. There's this idea of focusing on your abilities. So, it's very easy to get into a mind frame where you focus on what you can't do, what looks different from before. And so, there's this idea of really reframing that and saying what can I do now that's similar to what I was doing before? So maybe it's not exactly the same.

[00:10:10] So there's the idea of, okay, maybe you can't play like a full round of golf, but maybe you could do the nine holes or maybe you could ride in the golf cart and still play them. So, what can you do that still allows you to engage in the activities that you enjoy, but isn't as physically demanding or as fatiguing as it might have been before? So really thinking about, how do I modify an activity to be able to still participate in it? And so, work may be really important to you, and so how do you modify your work schedule, or your work demands? Or are there ways that you can spread out the really intense work activities across the course of the week so that they're not all bunched into one day and being able to again spread out those spoons that you might have in that situation.

[00:11:08] We also talk about developing coping strategies. So physical coping strategies could be something like yoga, or meditation, or taking walks. There can be more cognitive coping strategies where you're thinking of word puzzles, or journaling, or things like that. And then mental where you're thinking more of really being able to participate in therapeutic interventions where you're working on developing a toolbox of coping strategies for when things are more challenging. So maybe you're practicing progressive muscle relaxation

or deep breathing, some of those activities that might be able to support you during the times that are more challenging. So, I'm going to transition just now to talking about how to share information about your medical diagnosis. I think we all live in these different systems where we have our individual families, and our homes, and our interpersonal relationships with our romantic partners or our spouses. And then we also function within a number of different communities.

[00:12:20] So we have our school or our workplace, our neighborhood, the community that we live in, the government that we're a part of. And how all of those things affect us on an individual level and may affect how you want to share information about your medical diagnosis. So, I've broken it down into this idea of sharing information. And so, I think it's really important to think about who do you want to share this information with. So, thinking about your family, so your immediate family, your extended family. Who are the people that you trust and really want to know this information? And I think that it's really important to consider that you're not obligated to tell anyone, right? This is your information and I think it's really important that you feel comfortable and that you trust the people that you tell. There're friends that you may feel comfortable sharing this information with, and there's friends that you may not want to share that with.

[00:13:22] In terms of school, workplace, and community-based activities, I think some of the information about what and when to share with those individuals in those systems may be related to what services you're hoping to receive. So, if you have a child where you would really like a 504 plan for them to help with addressing some of the fatigue or potential cognitive vulnerabilities that he or she may present with, you may need to share that medical diagnosis to be able to ensure that the child is eligible for those services. The same thing with the workplace. There may be some people that need to know the diagnosis and some people who do not. And so being mindful of who you're telling and being very clear about where you would like that information to be shared and with whom in the environment. Then the same with community-based activities. Again, if you're applying for different resources within the community, you may need or want to share that diagnosis with people. Another idea is why?

[00:14:28] So, again, really setting the stage of like, is it necessary to tell people in that environment? Do I want to tell this person? Then is this person that you're going to tell someone that you can trust? I think that's a really important factor for people to be mindful of, and being very clear about the expectations that, I'm going to tell you this. It's very important to me, but I would appreciate it if you didn't share it with other people or if you could keep this to yourself, so that that individual understands where you want that information to travel. Or you may be a person who really would like that person to share your story with others, so that you don't have to keep repeating the story. And I think being clear about that can really help support you as well. So, what is important to share when you decide you feel comfortable sharing information? The name of the diagnosis, the symptoms that you experience. And so, it could be something like what that looks like for you now, what it could look like in the future, and what triggers you might have for relapses or recurrences and things like that.

[00:15:38] Then oftentimes people upon hearing these diagnoses or these concerns will want to know what they can do to help. And so, being thoughtful about like, is there identified behavior that might be helpful? Gosh, it'd be great if you could bring dinner on the first Thursday of the month, or it'd be amazing if you could help take my kiddos to school on this day or something like that. And giving them some type of action that can feel like they're doing things. Recognizing that that can be hard to come up with when we're in the midst of a storm. And so, giving yourself some grace if you're not able to do that as well. So, sharing information, when and how? So, I think the timing of disclosing a diagnosis can be really important. It may not be something that you do in the carpool lane, or it might not be something that you do at the big holiday event, that maybe you really find time to meet individually with a person and talk about what's happening. Location can be an important thing to consider. So, is this someone you want to tell in person? Is this someone that you have to

or need to tell over the phone? How are you going to set the stage for this to feel like a conversation where you were heard and have information shared with the person that you would like to?

[00:16:59] And then the amount of information to share. So, you don't need to tell everyone everything. So are there certain people that you need to just tell the basics to versus like a best friend, or a romantic partner, or spouse where you really want to tell more of the elaborate details, understanding that you are able to differentiate between different individuals in your life and what you're willing or wanting to share with them. So, the other big piece is managing the responses. So, when you tell people, you may find that you get a lot of unwelcome opinions, or recommendations that others are wanting to share. So, oh, if you'd only do this, or I heard about so and so who used this medication, or this vitamin and it cured everything. And if you just do that, everything would be better. Or the negative comments where you don't look sick, you don't look like there's anything wrong. And some of those really negative comments that can affect you when you're deciding to share information. Or the overly positive responses, right? The, everything's fine, you'll do great. It's not a big deal. At least it's not X, right? So, some of those things that can be really challenging.

[00:18:17] I think at the end of the day, it can be really hard to tell other people about your diagnosis, because you might be concerned about these types of outcomes that you might receive. I think there have been studies that have shown a benefit of individuals who receive social support and are able to actively plan their response to their diagnosis and treatment. And those individuals two years post a medical diagnosis are much more well-adjusted and report higher levels of quality of life. So even though I think this process can be really challenging and can potentially raise some very uncomfortable conversations, there is some research to support the fact that this process can be really helpful in supporting your long-term overall well-being. So, I know I have just a few more minutes, and I wanted to spend a little bit of time dipping down into this idea of, how do we manage some of our long-term emotions? And again, this I think is something that is an ongoing journey, and so not something that I'll be able to completely help within 30 minutes. But kind of gives you some ideas and some initial steps to start thinking about, how can I manage this in the long run.

[00:19:32] So the first is to identify some of our triggers for anxiety and for low mood. So again, starting with that healthcare journal, you can start to track, what are the days that I was feeling better and what was happening on those days? Did I use up all my spoons before noon, and thus was feeling really fatigued and tired, or did I have extra supports that day? And really looking at what you can do to identify what is making a good day good and a bad day not so great. Be mindful of those downward spirals that we can all be vulnerable to. So, the cascading effect of like, I had a bad day, it means I'm going to have a bad week, it means I'm going to have a bad year and trying to really be thoughtful and challenging those negative thoughts. Like that was a bad day, I wish it hadn't happened, but tomorrow will be a better day, and trying to stop that negative cognition that we can all engage in when we're having bad days. Working towards creating what are called upward spiral. So, what are the things that make you happy, and can we do more of those? So, this really gets into a type of therapy called behavioral activation.

[00:20:47] And we'll talk about some of the main themes in that type of therapy. But the idea behind it is really to identify some things that can make you feel better. So, we're going to actively start monitoring, tracking your mood, looking at the activities that make you happy and the activities that bring you down or make you sad. And then identify your personal values and identify associated activities with them. So, are you someone who really values time with family, or someone who really values his or her career? And how can we directly engage in activities that are going to help you to feel successful in those activities again. So, when we talk about some of these, there's a couple of different areas that we look at for your values. So, the first one is physical well-being. And so, we talk about, are you someone who you know views yourself as really valuing what you look like, or how active you are? And if that's the case, how do we help you re-engage in some of those physical activities that you may have enjoyed doing before?

[00:21:56] Again, recognizing that some of them might need to be modified, but really helping being able to get you back into those physical activities that you value. Another one would be, are you someone who really values mental and emotional well-being? And so, if that's the case, what activities can you do that help support that? So, you someone who really values meditation, or yoga, or can you spend some time with a therapist or a coach who might be able to help you manage some of the emotions and develop some of those coping strategies to help get you through this storm. Family relationships, oh gosh, I really love bedtime reading with my kids. So how do I make sure I have enough spoons left at the end of the day that I can be a part of the bedtime routine? And maybe your romantic relationship is really important. How do I carve out time for date night once a month, or how do we make sure that we have good communication skills on the days that are feeling hard so that we can look at how to strengthen that area?

[00:23:06] Friend relationships maybe something that's really important to you. So, I really want to be able to spend some quality time with my friends. How do I schedule that again making sure that I have enough ability to do that with all of the other stressors that are happening? Maybe you're someone who really values community. So, you want to be actively engaged in volunteer work. So how do you look at actively engaging in a volunteer organization that would help you feel validated and refreshed? Spirituality, maybe you're someone who really views church as an activity that's really valuable. And so how do you again preserve time and energy to be able to participate in that activity? Then hobbies and recreation. So being able to look at, gosh, I really want to be able to go hiking, or it's really important to me to do stand-up paddle boarding. And so how do I make sure that I have the energy or the adaptive tools that I need to be able to continue to participate in that task?

[00:24:13] Then educational and personal growth. If you're someone who continues to love learning, how do you enroll in some virtual classes? Or are there after work activities that you could go to where you could be able to learn a new tool or learn a new skill that you would help you feel like you're growing in that area? And then employment and career, focusing on what are your values in that area. Is your career very important to you? And if so, how can you continue to grow in that area or are there modifications that you need to make so that you can continue to feel successful? So, I think I have five minutes left. I can't see if there's questions. So, should I stop sharing? Would that be helpful?

[00:25:07] **Moderator 2:** Yep, thank you so much, Christa for this presentation. Dr. Levy our excellent moderator is coming up as we speak. There you are.

[00:25:16] **Dr. Christa Hutaff-Lee:** Okay, great. Thank you.

[00:25:17] **Dr. Michael Levy:** With five minutes, I think we can probably take a couple of questions maybe from the audience and online if there are any. Questions for Dr. Hutaff-Lee. Two right here.

[00:25:36] **Audience Member 1:** So, the biggest thing for me are those unwelcome responses or unwelcome opinions and recommendations of the things that you should do, the vitamins you should take. So, what is a good response to that that's still nice?

[00:25:57] **Dr. Christa Hutaff-Lee:** I mean, I think that's a great question. We probably all have that first response that pops into our mind that isn't so nice. But my recommendation would be to just gloss over it, and to be like, well, thank you for that opinion, I really appreciate it. I'll consult with my medical team. And then it shuts it down, but I think it is tricky.

[00:26:29] **Dr. Michael Levy:** We have a couple of questions on this side.

[00:26:37] **Audience Member 2:** Thanks for sharing, first off. Secondly, as far as trying to identify those values and where to put those "spoons" throughout your day, do you have any techniques or like worksheets that you found that best help you really identify it? Because if you have two that are like battling heads, how do you really find the best balance between everything?

[00:27:04] **Dr. Christa Hutaff-Lee:** I think that's a great question. I think there's times in your life where one may feel more important than another, and it could be that that varies significantly. There are some worksheets. So behavioral activation is an evidence-based therapy for individuals who have depression or just mood related concerns, or just are dealing with a lot of stressful situations. And so, it can be something that a psychologist or mental health provider would have accessible. And there are some worksheets available online as well, and I can work with this team to see if I might be able to share that with the individuals who've been attending this conference.

[00:27:53] **Dr. Michael Levy:** Okay. Thank you, Dr. Hutaff-Lee. That is very helpful. We'll go back to Dr. Harder.