

Community Perspectives Panel

Navigating Work, Travel, Setting Boundaries, and More

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[00:00:05] **Dr. Benjamin Greenberg:** This session was on Community Perspectives: Navigating Work, Travel and Setting Boundaries. I'll actually focus us, if it's ok, on that last part. I think we've heard a lot this evening about how do you navigate work, how do you navigate travel -- both physically and emotionally and cognitively. It's this last part that I actually find extremely interesting: the notion of setting boundaries because it impacts everything.

[00:00:30] And I'm curious from the panel members, if you can give examples of how there have been situations where either health, well-being, functioning, or everything you've been through have required, or would have benefited from, some type of boundary setting. What types of things come to mind when we discuss setting boundaries? So, Becca, if you want to lead us off, that'd be great.

[00:00:58] **Rebecca Salky:** Sure. Yeah, I think I've had to learn how to set boundaries with friends, with work, and what I can do. I tend to really need my rest, so I've had to learn when to say no, how to say no productively, and when to take my rest.

[00:01:21] I'd say it took me a really long time to even get to where I am now, where I feel pretty comfortable saying, "No, I can't do that right now." Definitely, I was a people pleaser most of my life. But life has been a lot better in the last couple of years, once I've learned how to say no to people when I can't do something. So, highly recommend.

[00:01:44] **Dr. Benjamin Greenberg:** Philip, do you want to comment?

[00:01:46] **Philip Rive:** Yes, thanks. I think I probably had to set boundaries on myself. I've been involved in service organizations, including Rotary, for many decades, and you train yourself there to say "yes" whenever you're asked to do or help with something.

[00:02:07] I'm learning now, because I'm probably the oldest on the stage here, that capacities are limited, and I'm better to do fewer things well than go for quantity. That means being able to say "no" to things that I would like to do, would have done in the past, but need to be comfortable limiting the demands I put on myself.

[00:02:34] **Dr. Benjamin Greenberg:** Leah, do you want to comment?

[00:02:35] **Leah Campbell:** My thing is: I've joked that, me volunteering for seven different organizations, I'm not good at setting boundaries. But I will say, going through school, through college, it was getting IEPs, so I could get those adaptations that I needed to be able to be successful.

[00:02:54] And just, really, time management and trying to allow my time to be able to recover from things. Unfortunately, I did too many all-nighters in college. I wouldn't do that now, knowing what I have. But definitely, time management is more of a thing on my side.

[00:03:13] **Dr. Benjamin Greenberg:** Yeah. So, there was a comment earlier -- I think it was from John -- about the notion of invisible disabilities. This notion of there are so many symptoms and issues that people manage that don't have an obvious outward manifestation. I'm curious if you can comment about, how -- if you have -- you've developed a language to communicate with people around you about those issues?

[00:03:37] Because so often, what I hear from my patients is, "Even the people closest to us in our lives don't fully understand what we're experiencing and finding the words and the ways to express it can be challenging." Have you found a way, when talking about boundaries or navigating work, to communicate with others about those issues?

[00:04:00] **Rebecca Salky:** I'll say that it's still been pretty hard if people haven't experienced it themselves or have been a caretaker, a caregiver, or even a physician. I think that they understand a lot better than even my sisters do. I am very, very open about my condition and my limitations. But I still think that it is a struggle, if you haven't directly been affected by it, to really, really empathize. So, I don't know if you guys have been more successful than I have.

[00:04:39] **Philip Rive:** I think of myself as a very unremarkable -- that's a medical term for pretty average and ordinary -- case of transverse myelitis. I came out of hospital after a week on steroids. During that period, I was roaming the ward with my drip bottle on the stand, and that was my walking stick. I was determined to move. But shortly after I was out, my disability was invisible, and I thought I could move pretty well without anyone detecting a problem.

[00:05:19] So, I'm always ambivalent when people would say, "Philip, my gosh, you're doing well." So, the implication, you have fully recovered. I would be a little proud of that, but also pissed that I was like the duck on the pond: sailing along okay, but an absolute shit show inside, mentally and physically.

[00:05:40] But in terms of people understanding what I was dealing with, I found it helpful, rather than give them a long lecture on transverse myelitis, to tell them that, "Look, if you can imagine something like polio or a spinal cord injury, the damage is permanent. It's variable from person to person." That seemed to get the issue out of the way.

[00:06:08] **Dr. Benjamin Greenberg:** Leah, any suggestions?

[00:06:09] **Leah Campbell:** For me, I just found that communication and just being open and honest. You unfortunately have to accept where you're at. For me, my blindness had happened early, and I've always looked as though I'm sighted and made eye contact with people, which was a super big compliment to me, but a deficit when you're going to a restaurant saying, "Hey, what's on the menu for this?" And they go, "Oh, look at this right here."

[00:06:37] And so, you really just have to vocalize things and find your tribe of those people that are understanding. People think my hands work and everything, but I can't feel. So, I may instinctively reach out for a glass, but if you don't make sure my hands are on it and I've got it, it's going to go on the floor, and it's going to be a big mess. So, it's just definitely communicating with those people around me.

[00:07:04] **Dr. Benjamin Greenberg:** Yeah, so, communication is so critical and so challenging, and there are different environments that we communicate in. I want to separate out part of the topic of the panel was the notion of work, and I'll broaden that to just outside the home, in the individual's or environments, whether it's paid work, volunteering, organizations, those types of things, versus communication with that inner circle.

[00:07:29] What I've heard from patients is different levels of frustration, and actually, a list of things that really annoy them. Philip, you referenced this, this notion of what I refer to as the, "But you look so good club," which is when you say, "I'm struggling," and somebody says, "But you look great." And a lot of people tell me, 'they feel pissed,' to use your quote, in that situation.

[00:07:57] Have you found, not just the words, but an approach to achieve a goal? So, sometimes the goal is a certain outcome, sometimes it's empathy, and Becca, you referenced this. Are there different techniques you use in the different situations? You said, you don't want to give a lecture on transverse myelitis, but for some people maybe you do want them to have a deeper understanding. How do you navigate how much to share and in which situation?

[00:08:30] **Rebecca Salky:** That is a great question. I'd say trial and error sometimes, and sometimes you do overshare and that's ok, and sometimes you might not share enough. I am very fortunate to get to work with Dr. Levy and his team who really understand.

[00:08:51] **Dr. Benjamin Greenberg:** Did you say fortunate or unfortunate? It's hard to hear. It's late in the day. Is he in the room?

[00:08:57] **Rebecca Salky:** I meant to say fortunate.

[00:08:58] **Dr. Benjamin Greenberg:** I think you said unfortunate. Just for the recording. You said fortunate.

[00:09:01] **Rebecca Salky:** Sorry, fortunate, very lucky, very fortunate to get to work with Dr. Levy and a team that really already understand my illness. I worked as a nurse before. It was really challenging to communicate to my manager and the nurses I worked with that some days I simply cannot come in. I don't feel well enough, my body doesn't feel good, or my vision might be off that day, and it's not safe for me or for the patients.

[00:09:29] And that was something that was definitely challenging, and I ended up having to set that boundary with myself and leave that job because it was too much on my body. So, I found a job that worked a little bit better for me with people who understand, and it's really made a big difference.

[00:09:46] **Dr. Benjamin Greenberg:** And if I can, just to push on that, because we hear about this topic in the workplace all the time, in general, what I found is, particularly in the United States, workplaces are not really structured to deal with the notion of good day, bad day. That tends to come up in annual reviews or performance reviews, the bad days end up counting against us.

[00:10:11] In your experience, it sounds like you made the decision to transition and find a different work environment. Is that the best -- I shouldn't say the best course of action -- did you find anything when you were

trying to work in the nursing role that helped in that communication? Or, and I'll be honest, a lot of times we suggest doing exactly what you did, that there will be some work environments that just don't match, were there any strategies that did smooth things over? Because this is common in our practice.

[00:10:43] **Rebecca Salky:** Yeah. I couldn't really find a balance when I was a nurse, and there was just a level of unpredictability that I couldn't handle -- my body couldn't handle. So, I knew even if I wanted to stay as a nurse, I just knew I needed to find a job that was more predictable, that I could ease my body into, rather than doing two night shifts and then a day later doing a day shift. It was just too much for me, and it wasn't something I was able to communicate in an effective way with my manager. So, for me it was the best.

[00:11:17] **Dr. Benjamin Greenberg:** And it may be even with effective communication some managers may not be hearing the communication or internalizing it.

[00:11:24] **Rebecca Salky:** Yeah. I do remember my manager got very upset with me when I ended up telling her. I thought I told her at the interview that I had vision impairment, but apparently, I didn't, because the year into the job, when I told her I'm really struggling, she got really mad at me for not disclosing that at the interview.

[00:11:43] And I was like, "I don't think that's actually legal for you to make me disclose that at the interview in the first place, but I'm sorry, I guess." So, I don't think it was the most healthy work environment in general.

[00:11:56] **Dr. Benjamin Greenberg:** I go back to the title of Pauline's conclusion to the book, Sandy, "Blueprints, there isn't just one."* And part of what's being described is plans change, what we do change. And Philip, you were talking about doing things, and I'm paraphrasing, "based on quality versus quantity," but you also talked about there are some things you say no to that in the past would bring you joy.

[00:12:29] If I can ask, how do you manage that? How do you talk to yourself? And you talked about setting boundaries with yourself to get to a place of acceptance for where things may be now, while working to change things in the future.

[00:12:50] **Philip Rive:** I don't know this, it's not exactly a workplace issue, but it's an example. I've run marathons between the late 20s; last one was at age 60, and my diagnosis was a few years after that with TM. And so, for years I was acclimated to physical activity on almost a daily basis, pretty arduous, and the measure was how fast and how far I ran. And if I ever had to stop and walk, that was a failure.

[00:13:25] So, there's a constant internal conversation when you're running a marathon: "I want to stop, I want to stop," particularly the last few miles. And it's taken me five years with my TM, when I've been able to be active, to appreciate being able to walk when I literally can't continue running because my gait's bad, my hip's hurting, my back's upset, my foot drops may be starting to catch my ball of my foot on the road.

[00:14:01] And I think that is an example of many of the challenges that I have faced. I have always, from the get-go, tried to focus on TM didn't take everything. It took a lot. It has affected everything, but I have to focus on what I can do. And TM, I'm very fortunate, has let me able to do a lot of things.

[00:14:23] So, sometimes it takes a long time to accept that I can't do what I could do, but what I can do now is still enjoyable, and I need to enjoy doing it rather than resenting not being able to do the things I can't.

[00:14:41] And that impacts other things, what volunteer work I'm doing, I scale back. I volunteer for the Long Beach Marathon every year as an old-time runner with a fun group of people. And this year, they got half-day

on each of two days instead of two or three days starting at 5 a.m., and I really enjoyed being there because I did not commit myself to three days.

[00:15:12] **Dr. Benjamin Greenberg:** Leah, do you want to comment, as you've adapted to changes in function and your interactions with the world? Has there been something that's been surprising in it, or something that's been, I guess, not to say a positive, but things that you wouldn't have expected as you communicate with people or interact with people?

[00:15:39] **Leah Campbell:** I wouldn't expect that, when I go to medical facilities, how many people automatically assume that, once they detect that I'm blind, then I automatically become nonverbal. That I can go into my doctor's office that I've been going to, and get a new nurse, and we come in, and they're like, "Okay, so how much does she weigh? And what are her symptoms?"

[00:16:05] And my parents have learned, "Don't say anything." They just look at me and that's when I'm, "Ok, so I don't know about them, but I can tell you for me." And then, once the doctor comes in, I'm like, "Ok, we need to talk about your new med assistant." And I've actually changed PCPs because my doctor couldn't remember that I was blind. If you couldn't write that on my chart, then you're not my doctor.

[00:16:33] **Dr. Benjamin Greenberg:** So, as we navigate through here, one of the topics that was on the list for the panel, it included travel. Everybody approaches travel differently in different abilities. What have either been the impact of travel that you've had to overcome, if any, and how have you adapted to it or overcome those barriers or obstacles?

[00:17:00] And I'll just say, as you're thinking about your answers, we struggle -- I think it's fair to say, Chitra -- every time we're planning Symposium, on how to manage the travel aspect. I mean, there are a lot of people in this room who came from a lot of different states, and we try to be as sensitive as we can, both in terms of location and structure. And long discussions that led to hosting this Symposium at the airport hotel to avoid shuttles, and cars, and everything else. And so, we try to learn from our community about what aspects of travel could we take into account when planning things like this.

[00:17:41] **Leah Campbell:** I can jump into that.

[00:17:42] **Dr. Benjamin Greenberg:** Please, Leah.

[00:17:44] **Leah Campbell:** For me, it's a lot. Because starting out at the beginning, it's going to be getting through security. So, we've upgraded from just TSA Cares to TSA PreCheck. For me, trying not to be as much of a burden on my parents for lifting, so I arrange lift assistance when I'm going to transfer from the aisle chair to the airplane seat.

[00:18:10] It's trying to minimize the potential for damage because my wheelchair doesn't fold. Then, it's when the airline does damage it, having those repair company for Global Repair Group that contracts with the airline, to be able to get a technician out there. And right now, I'm waiting to receive my new wheelchair, courtesy of American Airlines, that they broke permanently, and it wasn't replaceable. But it's a lot.

[00:18:40] Then, it's also how do you do the accessible transportation once you make those connections, keeping those numbers on record, having backup plans A, B, and C. When A falls through, because the elevator's flooded and only the escalator is working. And basically, we have the philosophy that when we go to a second place, trying to make one less mistake than we did the previous time.

[00:19:08] **Dr. Benjamin Greenberg:** I like it. Phil?

[00:19:11] **Philip Rive:** Thank you. This was a topic we got a warning was going to come up. So, I've got several things, and I'm aware that there are people that are dramatically more impaired than me. I progressed several months after my diagnosis and exit from the hospital with a walker. I used a walking stick.

[00:19:36] I think this travel issue is important. What's helped me from the get-go is to have a good reason to travel, and then I can put up with the inconvenience, or embarrassment, or whatever that happens along the way. It's still worth it. I've got family in New Zealand, family here in the States. So, within a few months, I was on the plane to New Zealand.

[00:19:57] And I've got a couple of points here: don't hide your light under a bushel. In other words, if you've got an impairment, then take advantage of the help that's available. So, I had to not be embarrassed about saying, "I need to board early," even though I looked pretty good, and I had a walking stick, and I could even walk the length of the terminal. I still needed to get aboard the plane earlier than everyone else so that I wasn't holding people up, that I could get my bag up in the overhead or whatever I was needing to do without feeling a pain in the ass to the rest of the world.

[00:20:37] I've got to fight for the window seat. Cindy and I have learned, over the last seven years, she likes the window seat. I need to sit at the aisle because I need to move a little more frequently. It used to be a lot, and I need to go to the bathroom frequently, initially because I wasn't too sure how much urgency I was going to be dealing with. Now that's a little more manageable.

[00:20:59] So, if it's a short flight, like coming here from LA, Cindy gets the window seat. If it's a 12-hour flight to New Zealand, then I get the aisle seat. And that was a problem, but I just put up with it and the rest of the world had to as well. Walking up and down the aisle -- as the aisles are getting narrower -- and when I'm wobbling from side to side, I'd be bumping people on the head and apologizing, but that's just too bad, price of doing business.

[00:21:31] And the other thing was, I joined the -- if you know your movies -- I joined the Brotherhood of the Travelling Underpants. And Cindy is not here; I think she wasn't feeling too great. I wasn't allowed to show you the full prop, but I carry a spare pair of shorts wherever I go, and I won't show you, because she said not to, spare a pair of underpants. And that's really just a matter of planning. It's a long time since I have needed them, but I think I have to be thinking ahead. I think I'm almost a bit PTSD about it. It's only happened a couple of times.

[00:22:15] And the other thing -- a couple of things I'll mention, and then I'll shut up, because Cindy is not here to tell me to -- is: does a TM, I don't like to use the word patient or survivor for some reason. but does a TM crap in the woods? And the answer is yes, because I like to hike still. I take a hike and fall. I trip and fall pretty frequently on uneven trails, but I still like to do it.

[00:22:49] And you can either limit yourself, stay in your motel room, or stay near to a bathroom, or you can go out on the trail. And I've learned to go on trails where there are other people around, because I shouldn't be alone and miles from company. But yes, I have crapped in the woods in Yosemite, and I have crapped in the woods and trails of North Carolina, and so shame is left at home.

[00:23:18] And I think I'm not going to continue much longer, but my experience with traveling comes under the guise of running with scissors. Our mothers told us, "Never run with scissors." Since my TM, I have felt

that I have had to run with scissors. So, I have done things that are risky. I have fallen over a lot, and I don't mind it. I lost weight, so that I didn't land so heavily.

[00:23:46] I work on my upper body strength. So, if I trip and fall forward, which is my MO, whether jogging or on trails, I'm less likely to break a wrist. And I have done things that I know are hazardous, whether it's swimming out further than I need to. I now swim with a float.

[00:24:08] But I want to keep living a life to the full, and I have to keep pushing boundaries, even though they're shrinking with age and other issues. And I mention it very gently with caregivers. We need to go out there and do stupid things, risky things, at the extent of our abilities. We need to fall and bruise ourselves and all those things, because that's what everyone else does. And we must do it, or our world shrinks, and that's uncomfortable.

[00:24:46] So, if you're saddled with a rare neuroimmune person in your life, then let them do some things that you're uncomfortable or you think are borderline, because you're doing them a favor. You can always pick them up and patch them up afterwards.

[00:25:04] **Dr. Benjamin Greenberg:** Well, I'm going to put the risk and the falling aside for a moment, but I'm just going to beg: when you write your book, that it's called *TM Craps in the Woods*. I will absolutely order that book.

[00:25:18] So, listen, I want to be sensitive to time. We could talk for a while, and I'm sorry to cut this short, but I just want to say just a couple last words. I want to thank our panel for sharing your stories, and your insights, and how you manage these various situations, and we greatly appreciate your openness and willingness to share.

[00:25:36] You've come to the end of this part of the program. We're going to take a 20-minute break to allow the hotel staff to come in and set up for the program tonight, that's being put on by the Can Do MS group. I encourage everyone to take the 20-minute break, and come back in and participate. There will be opportunities to ask questions, and have more of these conversations that we started, now with that program and tomorrow morning. So, let's give a round of applause to our panel.

* This was in reference to the book by Sanford J. Siegel Ph.D., *The Patient Experience with Transverse Myelitis: An Anthropological Perspective*
<https://www.sanfordjsiegel.com/books>