

Recorded April 2020. [Listen to it here.](#)

- ERICA WEBER: 00:05 [music] Finding new ways to connect with people to ward off things like social isolation, depression, anxiety. Thinking creatively about how to get our needs met, whether practically or emotionally.
- ANNOUNCER: 00:19 Welcome to this COVID-19 special edition podcast brought to you by Kessler Foundation. Social distancing is becoming the new norm in the days of COVID-19. While quarantining is proving to be challenging for many Americans, there may be additional social struggles faced by individuals with multiple sclerosis and traumatic brain injury. In this podcast, we discuss with Dr. Helen Genova how problems with social cognition may be exacerbated during quarantine, and how to reduce the impact of these difficulties on relationships in the household. Dr. Erica Weber also provides insight into how individuals with multiple sclerosis in traumatic brain injury may be feeling socially isolated right now, and how to find social outlets and resources to improve mental health in this stressful time. Listen in as Nicky Miller, our social media specialist, introduces our guests.
- NICKY MILLER: 01:18 During the COVID-19 pandemic, people are advised to practice social distancing and staying at home to flatten the curve. These practices offer minimal contact with other people and the outside world, and can be particularly challenging for individuals with multiple sclerosis and a traumatic brain injury. Today, our podcast focuses on how social distancing measures and social isolation can affect individuals with MS and a TBI. We open up our panel discussion to Dr. Helen Genova and co-host Dr. Erica Weber, who are experts in the field. Dr. Genova is the assistant director of the Center for Neuropsychology and Neuroscience Research at Kessler Foundation who researches social cognition and emotion recognition in brain disorders. Dr. Weber is a research scientist and clinical neuropsychologist in the Center for Traumatic Brain Injury. Welcome, doctors, and thank you for joining us.
- WEBER: 02:08 Thanks so much for having us, Nicky.
- MILLER: 02:11 Dr. Weber, I'll let you take the lead in this. But I wanted to start off by asking, Dr. Genova, can you explain the symptoms of multiple sclerosis and a traumatic brain injury, and why times like this can be challenging for those individuals?
- HELEN GENOVA: 02:24 A lot of my research focuses on social cognition. So we know that people with multiple sclerosis and traumatic brain injury can have a whole host of symptoms, whether they'd be physical symptoms, or cognitive, which means mental symptoms, forgetfulness, load thinking, etc. But one of the things that I focus on is something called social cognition. And we think that not everybody, but there is a significant number of people with both multiple sclerosis and traumatic brain injury who have the social cognition deficits.
- WEBER: 02:59 Now, that's really interesting, Dr. Genova, that there's this population that might be experiencing maybe more distress in this already pretty distressing time during the pandemic. What do you think the social cognition deficits might look like in this population, especially right now? What are they dealing with?

GENOVA: 03:19

So when I say social cognition, what I really mean is any mental skill that's involved in processing the emotions and feelings of others. And you literally are using these skills whenever you are with other people. So let's just say you're invited to a party, and you walk into a room and you see people in the room, and there's one person and they're smiling at you, and you process in your mind that they're happy to see you, so you're using your social cognition to understand how they're feeling. But then let's say you go into another room and you see that someone is angry, and then someone else is crying, so in your mind, you're processing, "Oh, oh. Something bad just happened here. Someone is sad. Someone is angry." So all of those skills, those are all social cognition skills, and we're using them all the time. So something like a pandemic, where we're all forced to be in our homes, that is really going to cause, potentially, some difficulty if you're already having problems with social cognition, and then you're forced to be inside all the time, and maybe you are actually interacting with the same people over and over again. One could imagine that those problems are really going to start to take a toll on relationships.

WEBER: 04:43

Right. That sounds like it would be pretty heightened if you're maybe having some difficulty perceiving what other people are either feeling or thinking. And now, you're kind of in the same environment with the same person, and of course, going through a lot of thoughts and emotions that we all are right now, that may kind of swirl a bit out of control. Wow. So do you think that this has to do with how people are, maybe, seeing emotions on a face, or is it a bit more how they're perceiving other people to be thinking?

GENOVA: 05:22

So I think it's really everything. So let's say you are now living with your family members, and so it sort of forces us to be more connected and to spend a lot of time with each other. That can be both a wonderful thing. I mean, you get to spend time with your family in a way that you never used to. But it also can--

WEBER: 05:47

[inaudible].

GENOVA: 05:48

Yeah. But it can definitely, like you said, heighten some opportunities for some interpersonal difficulties. So some of the things that we use in social cognition are what's called facial affect recognition. So if you are looking at someone's face, and you understand, based on their facial features and how they're moving the muscles in their face, that that person is sad, like I said before, or that person's angry. Or in the case of social isolation, that person is getting on your nerves.

WEBER: 06:23

Wow. And I bet that's even more of a problem these days because, well, first of all, I know that a lot of people are using things like sarcasm and humor to be able to cope in these difficult times. So you're requiring a lot more of those subtle social cognition skills. And then also, people are just more stressed, and when people are more stressed and have a lot more on their mind, it's really difficult to think clearly. So I bet that's a lot for a normal healthy brain to consider and being able to make those judgments correctly. So if someone already was having some difficulty with that, I could imagine this might be even more of a challenging time. So it sounds like you're saying that if people are noticing increased tensions and maybe people being a little bit more perfectly than usual, I guess is a way to say it, it may be that there are these difficulties in social cognition that are really coming in bear in this situation. So what

do you think is a good way for people who are experiencing this too to try to mitigate these challenges in their household?

GENOVA: 07:44

I really recommend that now is the time to just be very open and honest with your loved ones who you are isolating with, or you're inside with. Now may be the time to say to someone, "Listen, I'm just having a really hard day. I don't mean to snap at you, I'm just stressed. I'm anxious. I'm trying to get stuff done, and I can't seem to get anything done. And I'm just having a really hard time," rather than trying to rely on just understanding other people by looking at their faces, or trying to assume you understand how other people are feeling. I feel like now is really the time to just come right out and tell each other how you're feeling so that you're not trying to guess and you're not trying to use some of these skills when you're already exhausted, stressed out, tired. Like I said, just to be honest with each other, and to-- really, this is the time to open up the lines of communication.

WEBER: 08:46

That's a really good point, and probably, generally, good practice because sometimes it's really difficult. In clinical psychology, we talk a lot about trying not to be a mind reader, and how that can end up having some problems because you might make some assumptions about what people are thinking, and we may be wrong. But that leads us down a whole rabbit hole of new areas of where we've made assumptions upon assumptions. So by directly communicating or directly asking people, "Hey, what's going on? How are you doing?" or as you suggested, to say, "I'm having some trouble right now. I'm feeling sad," or, "I'm feeling frustrated," I think that's a great way to at least keep those lines of communication open. And this way, everyone's a bit more on the same playing field, rather than playing that guessing game.

GENOVA: 09:46

Exactly. No. I think it's really, really critical right now. And also, just to realize that if you're feeling stressed, probably your loved ones are too. And so some of these interpersonal issues you may be feeling are just a question of everybody feeling a heightened level of stress. And to give yourself a break and to kind of forgive yourself, as well as the other person. If you snap at each other, maybe just say, "Hey, you know what, of course, we're going to snap at each other. We've been only looking at each other for the last two weeks, and nobody else." So to sort of maybe just kind of forgive yourself for those moments and say, "This is hard. Everybody feels this way. And let's just try to get through this as best we can," and take a walk. Go outside, enjoy the nice weather, and not worry so much about these interpersonal issues.

WEBER: 10:36

Right. And I know you've done some work with mindfulness meditation, I wonder if that may be a good tool for people to use right now in order to be able to-- when you're saying they can maybe take that break or acknowledge those emotions, this may be something that would be really important right now.

GENOVA: 10:56

Yeah, absolutely. I think that mindfulness is a really wonderful tool that sort of anybody can use. So mindfulness is really just focusing your attention to the present moment. So you're not worrying about what's going to happen tomorrow, you're not thinking about what you said yesterday and the mistake that you might have made, or what's going to happen in six months. You're really focusing on right now, this very moment, and just paying attention to it. So something that everyone can do to practice mindfulness is just to take a moment. Take deep breaths in and out, focus only on your breathing, on the way that your body feels, on the sounds that you're

hearing right now in the current moment. If you're drinking a cup of coffee, to sit there and feel the cup of coffee in your hand, and to feel its warmth. And if you're outside, to listen to the sounds of nature. And why I think it's so important is, right now, there are so many any external things that we're worried about that so many of them are not within our control. The average person can't do anything to help this pandemic end any sooner, other than what they're already doing, which is being in their home. So rather than watching the news, and connecting to Facebook, and trying to figure out where to get the next roll of toilet paper, and, "Oh, no, there's no meat in the Shoprite," to just saying to yourself, "You know what, these are things I have no control over. But what I do have control over is where I'm going to focus my attention." And to just be present in the moment can do wonders for your psychological well-being, to just say, "I'm going to let all of that go. All the anxiety, all the stress, I'm going to let it go, and I'm just going to focus on my body and how it feels right now in this present moment."

WEBER: 12:58

Yeah. That's a really good point. And mindfulness is something that people work on for a long time in order to kind of learn how to do it and practice it. So definitely, it's not the easiest, but the nice thing, I think, it's getting a lot more a lot more attention right now, and there's a lot of really good online resources. I think even on YouTube, there's a number of clips that walk you through mindfulness practice. So there's a lot of resources available. And I would just say, it takes people a little bit to get the hang of it. So if you find it a little bit frustrating at first, the whole point of mindfulness is that you forgive yourself and move on, and just try again. So non-judgmental responses. And don't beat yourself up for having a challenging time. Being able to focus on the present moment because there is a lot competing for our attention right now. But it sounds, from what you're saying, that the benefits will really pay off and make it worth the challenge.

GENOVA: 14:17

Yeah, definitely. And I think one thing that you can do, sort of anybody can do, is to go outside and to just name five things that you can hear, five things that you can see, five things that you can smell, and really just tuning into what your senses are telling you, as opposed to what your anxiety is telling you, what the news is telling you, what social media is telling you, but really to just focus on, "You're in the present moment." And like I said, there's so much that we can't control, but this is something that we can control, and it's free, and you don't need a specialist. They're with you, and you don't need to-- I mean, there are classes available online that you could take to help you. But like you said, there's lots of wonderful YouTube videos. I really recommend videos by Jon Kabat-Zinn who started the program Mindfulness-based Stress Reduction. He has some really wonderful videos online.

WEBER: 15:19

And as you were talking about this, and how mindfulness is really helpful for recognizing that it's important to be in the present moment because there's a lot that you may not be able to control, it dawned on me that this often can be something that people with multiple sclerosis and TBI are very used to dealing with. Where, multiple sclerosis, you don't know necessarily what symptoms are going to be exacerbated the next day, or when your next relapse might be, or how long it might last. And with traumatic brain injury, you may be facing new challenges on a daily basis. So this sounds like, on one hand, something that these populations might be even more adept than people who maybe have had a little bit easier of a go of it. So

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this is something that I think is absolutely in the wheelhouse of these populations. And probably they could teach us a good thing or two about how to be able to cope in situations where you may not be able to control what's going on around you.

GENOVA: 16:33

Yes, definitely. I totally agree. I think that any population right now can utilize these techniques.

MILLER: 16:40

Dr. Weber, I'd like to talk a little bit about social isolation. Social isolation can be harmful and is linked to depression and anxiety. Can you discuss how this COVID-19 pandemic can affect individuals with MS and TBI in this regard?

WEBER: 16:55

Oh, absolutely. So I mean, we've covered two ends of this. All these social distancing measures really kind of create two camps of problems, or challenges, shall we say, that in one sense, while you're spending a lot of time with people, that may create its own set of challenges. On the other hand, you're not being able to engage socially like you normally would. And this could be really problematic for folks who are susceptible to depression and anxiety. And we know that people with multiple sclerosis and traumatic brain injury tend to have higher rates of these sorts of psychiatric problems than the general population. But this is also something that people are dealing with across the board right now. So the name of the game seems to be: finding ways to scratch that social itch and become connected with people in ways that, maybe, you wouldn't have been able to do so before. So how do we still be able to be normal social beings in this strange situation that we find ourselves? So this could be challenging if you are unable to find ways to think outside of the box and outside of the confines of your own home. But thankfully, we're in this great age of having a lot of technology available to us that really allows for much easier social connectedness than in previous generations.

WEBER: 18:33

So a number of things that people have been doing in order to ward off those sorts of feelings are: connecting with people over things like video chat, whether it's one-on-one conversations, or groups. There's a lot of platforms, be it-- a couple I could think of are things like FaceTime or zoom that allow multiple people to be engaged one conversation at a time. So if you usually met a friend down the block for a cup of tea, have a cup of tea over video chat. I know it's not the same, but it's some way to at least be able to be connected. Other options are, looking for the support systems that you used to have, be it support groups, let's say for-- particularly for MS and TBI populations, a lot of people rely on their monthly support groups to be able to discuss challenges that they face on a day to day basis. And we know that those social support networks are really impactful and really helpful in order to manage and manage your disease, and be able to feel like you're not alone in this fight. Well, a lot of the organizations, like, off the top of my head, the Brain Injury Alliance of America, and the National MS Society, they have great online resources. There's oftentimes a phone number that you can call for a support hotline. And whether that serves the purpose to connect you with other people just so you can have a conversation and feel like you're not alone, or even to help problem solve with difficulties that you're finding day to day due to the social distancing measures or the pandemic, these people are there for you, just the same they would have been in person. And I look forward to the day that we now kind of remember all these resources that we happen to stumble upon in this time, and then we can better use them in the future.

- MILLER: 20:45 Dr. Weber, what about family members, how can they be supportive at this time?
- WEBER: 20:51 That's a really great question, because as we all know, traumatic brain injury and multiple sclerosis, it affects the network. It affects a person, of course, directly, but it really affects the people around them as well. And making sure that the health of that network is strong, is really important. So on one hand, people who have a loved one in the household with these conditions, they can be critical in order to helping to recognize when the person with a TBI or MS is really struggling, whether that's kind of keeping an extra eye out on their mood or any sort of anxiety behaviors, or just kind of giving them a bit of more positive affirmation in order to make sure that we know that we can all handle this. On the other hand, family members need to take care of themselves because being a caregiver in a household with someone with a disability can be challenging on a day-to-day basis. This situation is probably increasing those challenges at least tenfold.
- WEBER: 22:13 So in general, practicing kind of good measures for keeping one's mood stable are really going to be imperative in these coming days both for people with these conditions and their family members. So that includes things like maintaining your physical health as much as possible. If you have regular medications that you need to take, make sure that you don't run out of refills and be in contact with your doctor. A lot of pharmacies are doing delivery if needed, which is very helpful. Also, exercise. I know that if you're used to kind of being more socially engaged with your exercise, this is definitely a change; or going to the gym, that's largely off the table at this point. But there's a lot of online videos available. A lot of websites are offering free trials at least for the next couple of months. You can take a socially distance walk outside. I've been definitely walking my dog out in the neighborhood a lot. And even things like gardening as the weather becomes nicer. And also, it's important to keep in mind nutritious meals to keep your general system functioning as well as possible, and avoid any sort of mood dips that might happen secondary, to say, things like blood sugar. And sleep. Sleep is important. I know it can be tempting to take this time at home and be a little more lax with the sleep schedule, but this is really where you want to stay on schedule, practice, good sleep, hygiene. And all in total, having the household stay on these sorts of good general behaviors can keep everyone's mood stable. And I really like the idea of finding an accountability partner. So having someone else keep you on track. So whether or not that's the person with the TBI or MS needing these reminders to keep these behaviors at the forefront. Or maybe it's kind of a family goal that we're all kind of keeping each other accountable to make sure that we're staying as healthy as possible, and doing things that are positive for our mood. So this really can be a team effort. So family members are critical at this point, and also needs to take care of themselves. So let's all do it all at the same time.
- MILLER: 24:48 Dr. Weber, what about people who can't be physically there for their families? Is there anything that they can do remotely?
- WEBER: 24:54 That is definitely even more challenging and heartbreaking, to say the least, at this point. If you have a family member with a TBI or with MS, you probably always have that feeling that if they're not right there, that you're wishing you can help out, or that you might worry about them. So that's really going to ramp up as we're not allowed to see those people. So that's where I'd really say, schedule times to connect,

and still maintain and create those bonds. This is a challenging situation for everybody. So being able to share those experiences can really help provide that emotional relief that we might be needing, even if we don't recognize it. But use whatever resources that you can. So whether or not it's-- let's say if you have a loved one with a disability in a different state, either if you could take a little bit of time to look into what resources might be local for that person. So finding, say, a local meal delivery service, that might be helpful. That could really help ease that person's ability, because it might be challenging for individuals with cognitive problems to be able to think creatively about these different solutions. And frankly, at this point, it seems to be an all-hands-on deck. If someone has a good idea, share it. This has been a very creative time, I think, for people to share what's been working for them and what hasn't, and being open and honest about where you're succeeding and where maybe you're failing, because not only does that help yourself be able to put things in perspective and come up with new ideas that work better for solving future problems, but you may be saving someone else a little bit of grief, or validating their experience as well. So being able to reach out in ways that are socially important but also practically useful, I think, are going to be really helpful in the coming weeks.

MILLER: 27:17

These are all great suggestions, Dr. Weber. I think a lot of people will be able to relate to this. I wanted to also ask about, what are some behavioral and emotional changes that you can talk about for each group?

WEBER: 27:33

Yeah. So this is really a time where we need to be vigilant on being aware of what we're experiencing. So things to keep an eye out for in terms of depression and anxiety, in particular, are keeping an eye on your mood. Feeling sad to the point where you're feeling sad for, say, most of the day or for number of days in a row. Also, eating and sleeping are always big indicators of how your body is functioning and how your emotional health is. So if you find that you're having a lot of trouble getting out of bed in the morning, or are sleeping much more than you usually did, or on the other hand, not being able to sleep, or feeling very drowsy during the day, that may be a sign that you might need some more support. Same thing with appetite, if you're eating a whole lot, or really have no appetite at all. So any of those sorts of extremes are important to look into. And I want to at least normalize some of this, that this is a stressful time and it's really normal to be feeling sad and having less hope for the future than you might have before. But check in with a loved one who can give a sense of, if this feels like something that needs more assistance or not. So it's really a good idea to keep those lines of communication open with other people to see what their thought is on whether or not you might need more support. And at least Kessler Foundation here is based in New Jersey, and I want to at least give a quick note that there is a mental health hotline for New Jersey and across the board, lots of states, probably all states have them at this point. But the mental health hotline for New Jersey is 1866-202-HELP, and HELP is and help is 4357, and that's for free, confidential support. They're there from 8:00 to 8:00, seven days a week, by trained specialists. So that's one example of many of these sorts of hotlines and online support mechanisms that are available in this time. So I'd really encourage people to use those if you feel like this is becoming a little bit too much for you to emotionally handle.

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- MILLER: 30:28 Talking about support and resources, Dr. Weber, what about virtual therapy, is that a method MS and TBI individuals could look into?
- WEBER: 30:38 Absolutely. And this is really an evolving territory by the day. A lot of clinicians have been folding telemental health into their practice, and usually, it's been used for individuals who have difficulty getting out of the house, or in rural areas and not really near their provider. But in the last couple of weeks, use of this has really skyrocketed. Of course, now there's a scramble to make sure that billing is going to work so that insurance providers are going to approve these services, but from what it looks like, this is becoming the new norm. So there's a lot of great online therapy options. And generally, going through the same process and speaking with a therapist that you would typically find, whether through your insurance or through recommendations from your providers, those individuals are often the ones who are now converting their practice into telemental health. And the benefit there is that you're not traveling, so you're physically as safe as possible. And so it may be easier to provide access for people who might not have thought to get services before. It does also sometimes create some challenges. So you want to make sure that you have access to a space where you feel comfortable that you're able to discuss things with a therapist in sense of privacy while you're in your own home. But in terms of overall privacy, this is something that the therapists and the health platforms have been working out. And there's also a number of newer services that are kind of coming on board to provide new avenues for telemental health. So that would be worth looking into as well.
- WEBER: 32:46 So in summary, the COVID-19 pandemic is creating a lot of new stressful situations for everyone. This is definitely unprecedented territory, but we really want to be mindful of how it's affecting the populations that we at Kessler Foundation tend to work with. And today, we've been highlighting challenges that might be experienced by people who've had a traumatic brain injury or MS. And this can be really generalized to anyone who might be experiencing some cognitive difficulties in their day-to-day lives. But it also sounds like there's a lot that we can now do to be able to mitigate these difficulties, whether that's finding new ways to connect with people to ward off things like social isolation, depression, anxiety. Thinking creatively about how to get our needs met, whether practically or emotionally, and finding new ways to be able to connect with the people who we are quarantining with. This is going to be memorable, at the very least, but the populations that we tend to work with, people with a TBI and MS, they know how to overcome challenges and difficulties more than any of us, otherwise. So I really think we can work together and be able to do this to come out on the other end of it. So thank you, Nicky, for being able to bring us together and talk about this really important topic. And I think we've learned a lot. And I'm glad that we were able to connect even via webcast today.
- MILLER: 34:31 Thank you for joining us, Dr. Weber. We are all in this together. We understand that people are scared and concerned, and we hope that these resources provide a sense of reassurance.
- ANNOUNCER: 34:46 [music] Thanks to host Nicky Miller, co-host Dr. Erica Weber, and guest Dr. Helen Genova for this discussion. Tuned into our podcast series lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. In new





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episodes, our experts weigh in on the impact of COVID-19 on people living with disabilities. And they talk about how research that changes lives continues the Kessler Foundation. Check back soon to listen to more COVID-19 podcasts. Look for the link in the program notes. Listen on iTunes, SoundCloud, Spotify, or wherever you get your podcasts. This podcast was recorded on Wednesday, April 1st, 2020 remotely and was edited and produced by Joan Banks-Smith, creative producer for Kessler Foundation.