

COVID-19 Q&A: Mental Health and Self-Care Considerations

>> Michael Stewart: Hey, everyone. My name is Michael Stewart. If you are joining us now, we want to thank you. We are going to get started in just a few minutes. Thank you for joining us today on this call.

So, again, my name is Michael Stewart. Hi, everyone. I work with the OI Foundation as the regional program services manager. Today, our session is going to be on mental health strategies and self-care during the COVID-19 pandemic. Before we get into some of the larger issues today, I wanted to go over some of the procedures for today.

So, one thing is, again, as you can all see, the OIF is practicing safe social distancing, so we are all working from home, and it looks like many of you are also at home. So, again, we have muted your microphones, and we are going to keep your microphones muted throughout the session, just so that we can hear the expert information from the speakers.

If you have used Zoom before, you know there is a chat feature built into this, and we ask that if you have questions for the speakers or comments, write into that chat feature so we can hear from you, and we are going to do our best to funnel that information to our speakers.

Also, one thing new we are doing this session is that we are going to be -- we have live captioning for this session, so if you go to your -- to the menu bar at the bottom, you'll see the closed captioning. There are different ways to view this. So, one way is you can go to closed caption, view full transcript, and you're going to see an automatically generated captioning system with time stamps. Also, if you want, we have posted a link, and we can repost it as well, where we have a -- actually, I'll go back to the chat feature -- [off mic] -- that's great.

You are going to see a link. I'm going to post it right there, StreamText.net player for our event. If you open that in a separate browser window, you should be able to see a live stream as well of captioning for our services, and we have the great Mike from ACS, who is going to be live captioning our event as we go.

Mike, I just wanted to -- I see that you have put into our thing as well, and so he talks about -- we are not going to be hearing from Mike, but we are going to be seeing Mike's work throughout the session.

I also see that it looks like Tracy has just joined us. Can we make, some of my colleagues, can we make Tracy a cohost so we can unmute her real quick?

>> I think I'm unmuted. Am I unmuted?

>> Michael Stewart: Fantastic, hey, Tracy.

>> I was unable to get on. I hope everyone was able to get on start. Are we ready to start, Michael?

>> Michael Stewart: I believe so. If you have questions about the captioning, in general, we are not going to be stopping the speaker's presentation. If people have questions about the captioning about how it's not working or it goes out for any reason, we would stop the session only for that, so, please, let us know. We want to make sure that you guys are getting this information and that we are being as accessible as possible.

And just real quick, while I go on gallery view, can you do a thumbs-up if you can hear me well, just real quick? I want to see a lot of thumbs up. Cool. Thank you guys so much. I appreciate that, little sound check. And with that being said, Tracy, I'm going to hand it off to you.

>> Tracy: Great. Thanks, Michael. Hi, everybody. For those who don't know, I'm Tracy Hart. I'm the CEO of the OI Foundation, and welcome to this afternoon's session. As you know, during this very challenging time, we at the OI Foundation are going to make every effort to provide you with the most up to date information that we can from our experts. And that is in all areas, as you can see today, we have a very interesting topic and one I'm so appreciative of -- for the expertise of our two presenters today.

Just a reminder that this is not an official counseling session. It's an information session and our two presenters are not experts on COVID-19, but they are experts in their field. So, with that, I would like to introduce our two speakers.

Our first is Dr. Kara Ayers. Kara is the associate director of the University of Cincinnati center for excellence in developmental disabilities and she is also a member of the board of directors of OI Foundation.

And then -- and she is a long time OIF volunteer. So, Dr. Ayers, I'm going to turn it over to you, and thank you to both of you.

>> Dr. Ayers: Thank you, Tracy. Yeah, I was excited about the opportunity to talk about this, because I know it's been heavy on my mind, as well as someone with OI and also someone in the mental health field.

Michelle and I wanted to share our own disclaimer. There we go. Just as a reminder that you're going to be seeing more of the term telepsychology or telecounseling, those kinds of terms, because many people are moving some of their medical or their mental health treatment to online through this time. But today's session is not going to be that type of a treatment. We are just going to be talking about these issues and having a chance for you to share your questions too.

So, start thinking about those and putting them in the chat box, because Michelle and I are both really excited to have the opportunity to dialogue as a community about this. That's what really makes today unique.

So, here is a picture of me. So I have Type V OI. I'm also -- my husband has OI. We have three children. So this has really affected our family in a lot of different ways. I'm now working 100% tele-remotely, and I'm also following the guidelines in terms of self-isolating, because both my husband and I are considered high risk for this.

So, I have got my contact information, and Michelle has hers as well on her slide, and I'm going to share an opportunity for something specifically that I would like you to reach out to me in just a second. But, first, I thought it would be helpful to talk about what you might want to look for in terms of changes in your mental health during this time. I think that when we think about changes in mental health, sometimes we think about the more obvious, like worrying more often or feeling kind of down in the dumps or blue or what we might term -- consider more like depression. But many people don't realize that changes in our mental health status can come out in a lot of different ways. So, if we find ourselves

sleeping more or sleeping less, disturbances in our sleep; we can also find ourselves being less able to concentrate on things; we might be more irritable but not really know why. So it's a good opportunity to kind of step back and reflect on not only your own behavior, and if you've noticed in any changes in it lately, but also, it may give you some new perspective on the behavior of those around you, because it's not always an obvious connection between A and B. So we may not know that we are feeling irritable, because we are feeling stressed out about the changes in our health and also all of the changes around us, but we can kind of have these different changes in ourselves and not realize that they are kind of our mind and our body's ways of tipping us off that we need to watch out for our mental health at this time as well.

Our body can also reflect stress and anxiety in different ways. Some people tend to feel it in their stomachs, with stomach pains or cramping or kind of trouble eating things that they wouldn't normally have trouble. Other people have even reported increases in their everyday pain, and that can be related, too, to how we are functioning mentally. So our connection between our mind and body is not understood fully, but we increasingly know there is a strong connection there. So don't disregard those changes, what feels like bodily signals but also in your mental health, more like mind signals.

I think another piece of this, too, for all of us is trying to find a balance between how do we remain informed enough. There's so many changes, especially in the last couple of weeks, things were changing sometimes on an hourly basis, but how do we remain informed of all of that but also not become too overwhelmed. So, and really, that takes a while to sort through which types of media are helpful for you, but not too overly triggering where they really hype up maybe your feelings of anxiety or feelings of worry or helplessness in this time period. So I think we are all having an opportunity to kind of figure out, okay, this is a way that works for me. This is a way that doesn't, and it's different for all of us. There's no one -- one right way or one wrong way. Some people appreciate the direct sources of things like press conferences. For other people, it may be more helpful to read a quick summary or even get a quick summary from a trusted friend that you know will give you accurate information.

And, again, as Tracy said, none of us yet are experts in COVID-19 or the response to a pandemic, so we are all figuring out what are ways that we may tailor our approach to media and also our interactions with others around this topic.

I think that last week's webinar with experts gave us an opportunity to hear from Dr. Glorieux and Dr. Sandhaus about unique concerns to people with OI. We can catch that, it's recorded like this one will be, and you can catch up on it if you missed it. For many, it can feel lonely to go through the experience, because while the whole world is literally going through it, not everyone has OI or has the same questions that are largely unanswered by the public's response to this. So it can be helpful to connect with our OI community, because you are not alone in it. It can just feel like it at times.

Another thing to consider is how changes to your day-to-day routines may be impacting your health. So I know there are some funny memes out there noting how some people are really excited about working from home now, but now that we are about a week or two weeks into that, people are really missing those everyday connections, whether you were going to school or work or even just out shopping, you're not having the same opportunity to engage with others. So, some of these memes are reflecting that people are kind of over it now and want to get back to their day-to-day routines. And as much as it might have sounded great to never have to change out of our pajamas, now we are missing that human connection.

So there's some things that we can kind of re-create in our everyday routines, and I think this is a little bit easier to do for children. I know with our three kids, we are trying to think of ways to structure their days in somewhat similar ways to what they used to be, because we know that that can offer a sense of security, and it can help with things like anxiety. And so doing that for yourself, too, may be really helpful. If you typically have kind of a wind down routine that you went through after you got home from school or work or before you went to bed, it's important to still try to keep those things. It can feel a little artificial at first, but it can really be helpful for your mental health in the long run.

I also wanted to make a note about a specific fear that some in the OI community have reached out to me about and I also work with in my day job approach of this, is the fear of what if people with OI do need to be hospitalized at this time. The hospitals in many areas are overwhelmed, and how would our care needs be met. And even another concern is if we had COVID-19 and we needed care in that way, there has been some discussions about rationing of care, based on disability, and that can be a really scary topic to consider. I don't think it's one that many of us or our society has considered before this pandemic. And it's one of those things that can make you feel helpless because there's not a lot that it feels you can do at this time about that. But I do want to encourage you that there are a growing number of people within the larger disability community that are saying I think it would at least help to reach out to the hospitals that are kind of designating these policies of how to ration care and express to them that people with disabilities have high-quality lives. Hey, we kick illnesses and broken bones all the time and return back to our lives, so we need that same high-level of care that everyone else would have.

So I am kicking off a work group around this, but if you're interested in taking part in such an activity, we would be working on facts sheets for hospitals to learn more about that. Feel free to email me, and just let me know, hey, this is my email, and I would like to take part in that work group. And it can be an international group. You don't have to live in the US.

It won't be a group that I'll provide updates on the topics, because there's so much of that going on already, so there will be more of a work group. And I think it relates to mental health, because at least for me, one way that I cope is to do something about it, whether it to be to express my thoughts on something or learn more about it, and this will give us an opportunity to do something about a really scary part of this pandemic that has definitely crept into the minds and worries of many people with OI.

So, I wanted to get a little more positive about what we can do in this time, and resilience is a strength among our community. We are experts at bouncing back after hard times, and really harnessing in on those superpowers by -- I'll call out Michelle. She had given a good quote earlier in the day that she has been training for this self-quarantine her whole life, and she has been knocking it out of the park. And I agree in many ways. We have had to do this before. We haven't had much warning that we are going to break and we are going to be home for an extended period of time. If you live on your own, maybe you didn't have a chance to stock up on the toilet paper and things that you needed before you had that broken bone. So we have developed scoping skills and we have things that we can share with other people, like grocery deliveries are an awesome thing. I was using it way before this. And we need to remember that as a community, because I think in many ways this is a scary time, because we feel really vulnerable, so we need to remember that we have these strengths that we can tap into right now to really help us get through this time.

And keeping a strong mental health, not being overly positive or not authentic, but keeping your mental reserves strong can really also boost your ability to stay healthy at this time too. So I think that's important.

I also wanted to show you, so I queried a small group of women with OI and asked them, "What are you doing right now that's helping you cope with this time?" And I got a ton of responses already, and this was just the first week for most people, of being self-isolated, and so these are on the slide right now in a word cloud. And you can see that people are really utilizing talking with others with OI. They were participating in things like baking, audio books, different treatments. They were learning about their OIs in many different ways than they had. I saw people in a chance we had to chat last week about our lung involvement with OI related to COVID-19. For many people, this was the first time that they were realizing that our lungs were involved, so that's a fantastic benefit of education for the community. There's lots of things that we can learn from each other, ways that we can cope, and I know we'll get through this together, but I'm looking forward to your questions, and I'm looking forward to hearing from Michelle now about what she is going to show us.

>> Dr. Fynan: Yes, beautiful job, Dr. Ayers. It's always a pleasure to be speaking with you, and hello to my OI family. For those of you who don't know me, I'm Michelle Fynan, and I have Type I OI. I live down here in Florida with my husband and my two girls. Addison is five, and Avery is two, and they both have OI as well.

So, in addition to being a mom, I'm also a therapist, as Tracy mentioned. I have been doing online therapy before we had to, and also I'm an online instructor. So that part, I didn't have really a hard time with transitioning to. However, now that the girls are home, you know, operating under that schedule, with them kind of popping into meetings and setting boundaries and things of that nature, it can definitely be stressful, so I experience the stress on that end. So, not only are we stressing about the illness, COVID-19, we are also concerned about how it might affect us, and also, you know, there's that level of heightened anxiety that goes along with it. Kara talked about, you know, the mood changes that we should be aware of as we are navigating these uncertain waters, and something to also consider is that some of the symptoms of anxiety and some of the ways that our body communicates anxiety to us can mirror that of like, oh, well, am I sick? That shortness of breath, I have got chest pain now because I'm having, you know, some panic creep in, and it can really lead you to think, you know, that it's the virus, that it's a heart attack. We can get really extreme. So I think it's important for us to pay attention to our body, to also recognize that this stress, if we are allowing those negative thoughts to creep in, and if we are watering them so that they continue to grow, then it's -- it's a little bit difficult to have a clear head through all of this, and that's ultimately what we need, right?

And it's difficult, too -- I have had friends in our OI community share that they are kind of reliving some health-related trauma. Some of us who have already known how OI affects the lungs, maybe you've gone through hospitalizations because of things like pneumonia, the flu, and you have had compromised lung function. This can really bring those traumatic memories, and it can be pretty triggering. So, it's important for us to just recognize this and to be kind to ourselves, again, as we navigate these waters.

Like Kara said, you know, we want to find that balance between staying informed but then also not diving in and living there when it comes to all of the news and the reports, right?

So, putting a limit on maybe how much time we spend can be very helpful. Finding a source that is reputable and also reliable, like Kara mentioned, having a friend kind of curate the news for you as we go through, and, again, recognizing that you are making choices for your health. You do have control in that arena, and what you're choosing to do to support yourself during this time. You're doing everything right, you know, you're showing up today to watch this, you're getting that support, and that's what matters most too.

We talked a little bit about the changes to our day to day. I want to talk about parents, too, if you have OI or if you have little ones with OI, that now we are home, and we might be fearful of them getting injured, right? I know that I had a talk with my two little ones, who really like to push their boundaries and their limits. I had a talk with them, and I was like, listen, you know, it's very important that we stay safe right now and just kind of letting them know that we want to be extra careful now, because I will cast you, but I don't want to have to do that. And we'll be, as Michael reminded me, we'll be having a session on that, where we go over these measures, right? But just having them developmentally be aware, you know, as far as like appropriate developmentally, education-wise, being aware that now is not the time to be jumping on the bed. You know what I mean? And just talking about the importance of safety, washing hands, things like that. And then to reframe it, too, because I found myself kind of getting caught up in that "what if," and we can very easily go there. Our automatic negative thoughts are like ants, right? There's never just one, and they can infest the place, so to kind of catch myself and not stay in that what if, I really kind of sat with the fact that, you know, when else would I have this opportunity to have them home with me? And the experiences that I'm having with them are ones that maybe I wouldn't have had if this didn't happen. And I also found that I'm not so worried with every phone call that comes in, because I realized how stressful I found it while they were at day care and not within my little line of sight, that I was always kind of worrying that any phone call that came in was day care telling me that they are injured. Right? So, they are home, and I'm allowing myself to bask in the idea that, you know, we are safe together, and we are going to take care of each other, no matter what.

And I think kind of speaking to the resilience that Kara brought up, you know, we have a unique perspective in living with OI in that we have been shown, over and over and over again, for some of us, that this too shall pass, that healing can happen. We have gotten gritty. We have recognized that, you know, it can be hard and painful for a while, but we'll see the other side, and I think that that's important because we are able to kind of draw on those perspectives and those experiences and have that be the lens through which we try to view this. Right?

We also have the opportunity to use technology to stay connected. We talked about that. We have got this wonderful meeting. We are using technology right now to connect from all over, and I also want to encourage you to now look at what other assets you might have in -- maybe there is an OI support group in your area that you never checked out. Maybe there is an OI Facebook group that you want to start. But I think that kind of leaning on your OI family, particularly in this time, as we do see things from a shared perspective, it can be very helpful in calming the fears and recognizing the fears, calming the anxiety and getting support.

Other assets that are available to you, there's a ton of apps that can also help with recognizing maybe symptoms. We could do some symptom tracking. We can maybe try out meditation for the first time or use some apps in order to get better sleep. Some off the top of my head, that I'm not endorsing

and I'm also not getting paid for any of this, but I have tried them. Headspace, that's a good one. Calm, there's a mindfulness app, and Kara had said before that, you know, sometimes it's going to feel -- it might feel a little forced sometimes, because maybe it's new. Maybe the idea of doing a gratitude journal can feel a little forced, but in practicing these tools and just kind of loading up your toolbox with different things, you might find that these become some of your favorite things that you will then have as a habit to continue when we are past this.

So, in addition to that, Kara mentioned mental health professionals are going online, and I think that that's a wonderful thing for accessibility. That was one of the reasons why I have had an online practice, because I wanted people in my area to not have to worry about transportation or injury. I specifically work with people with disabilities. I'm a relationship coach and a sex therapist, and I do a lot of couples counseling as well, where a disability is involved. So there's accessibility there, and if you don't have a therapist and you need one, then there's -- I wanted to just point out that psychologytoday.com is a great resource to do a little search. You can see if there's someone who takes your insurance. You can find they are nearby, if they do telehealth. You can look at different specializations that are involved. And then, also, there is the crisis text line. That's crisistextline.org. And that's another wonderful resource if you're feeling just not right, and if you just really need to talk to someone, if you're having any -- feelings like you're in crisis, if you go to this web page, you get support. One of the first pop-ups that happens when you go to the page is are you anxious about COVID-19, and you just want to take to someone, we are here. And, you know, just being able to have that knowing that you are not in this alone; we may be isolating, but that doesn't mean that we have to not be socially connected, and I think that the internet gives us the wonderful ability to still connect.

And I also wanted to point out that the things that we are looking at now in research, like lung function being one of them, as a very important part, there's opportunity for you to voice your concerns about what you want OI research to be focused on. So, now that you are home, I want to kind of plug patient-centered outcomes research. It's PCOR, and it's research driven by the OI community about our needs, about our concerns, and for me, mental health is one of them. And I think that we would love to hear from all of you and have our research driven by us, right?

So, that is where I am at. I know that we are going to be doing some questions and answers, and I can pass it off to whoever needs that.

Michael, is that you?

>> Michael Stewart: Yes.

Kara and Michelle, thank you so much for that presentation. I am going to turn off the shared screen, but, Kara, if you want to turn it back on, you're welcome to. And what we are going to be doing now is we have gotten a few audience questions already in the Zoom group chat feature.

To our attendees who are just joining us, we are going to be keeping your microphones off throughout the entire session, but if you want to communicate with us, please type your questions and comments into the chat, and we are going to be try to get to as many of these as possible in the next 30 minutes.

So, some questions we have been seeing so far is one -- so, first off, in regards to the other app recommendations, some of our people are talking about, the 10% happier app is a great meditation app too and has a podcast.

I also see people recommending Sleepa, with an A at the end.

Headspace is offering free mental health counseling to medical frontliners, nurses, doctors, hospital workers for free, so that sounds like a great service to.

I want to jump into some of the questions that we have been getting so far, and, again, if you have any questions, please type into the comments. We'd love to hear from you.

Living by myself, my concern is if I were to get the virus and I had to go to the hospital, I know they wouldn't allow a friend or family member to come along. So how do we go about advocating for ourselves if we get really sick? In the past, I have always depended upon my advocates to help me when I can't speak for myself.

>> Dr. Ayers: Yeah, I can try to start with this one. This is one of those frustrating places, because there's no great answer that's going to be a clear solution for this, because many hospitals are clamping down on these policies, for good reasons, in terms of infection control. We are even reading of cases where moms are giving birth in the hospital without their partners with them, because of these hospital policies.

One thing that is important to know, though, and that can help is to know your rights and that your civil rights don't pause because of this pandemic. So, the Americans with Disabilities Act is probably -- for those of us in the US, is probably the most applicable in terms of that it could be a reasonable accommodation to ask for someone to be with you, whether it be for your advocacy needs, but also you may need assistance with transferring or whatever it may be. So, from a policy sense, and sometimes that's where I shift in my own trying to coping with this anxiety, because I want to think about what we can do to make this more fair and make this more safe for our community really. So I'm keeping a watch on a lot of the different bills that you're hearing go through, and in our media, on the US side, again, what you're hearing a lot about is the stimulus package, but what you're not hearing about is a lot of the little things in here, one of which is for people with paid caregivers to take them to the hospital. That's really interesting, because we in the disability community have been fighting for it for years. If you have a caregiver that know how to care for you, you especially need them in the hospital. But in this instance, some people have had that light bulb moment that, yeah, people with disabilities need people especially in the hospital with them. So I can't promise that it will work in every hospital setting, but don't give up on advocating that even if you hear the blanket policy, really trying to express that you have needs such that you need that extra advocacy boost.

One last thing, too, is that if you haven't already, one thing that help put my mind a little bit at ease is I reached out to my PCP and said, we are fine, we are healthy, but if we were to take a turn, which hospital would you like us to go to? Because I knew all of those I had answers for an orthopedic issue, but it feels like everything in our world has changed and been turned upside down. It was helpful to hear from my medical provider to help establish a plan. No perfect answers, but it's definitely a fear shared by many of us, and there's a few things to do. Michelle --

>> Michelle Fynan: Yeah, I love that, and I'm going to now do that, but to piggyback on having a plan, Susie Wilson, for those of you who may know her, has been doing talks at our conferences for quite some time now about self-advocacy, and one of the things that her and Dr. Kathleen Ragio have worked together on is having a binder together with your medical history, you know, having all of your information in place so that it's written down so that you do have directives. Also, she recommends having a medical alert bracelet, things of that nature, just so that your information is organized and not just relying on you communicating it verbally. And I think that can even be something that it's like, okay, maybe I can make some time now to create that and carve out some time, and it can be something that does alleviate some anxiety, because, again, like Kara said, we are doing something about it.

>> Michael Stewart: Thank you so much. And, also, I want to make a quick plug. At 5:30 today, we are going to be having a talk with some orthopedic surgeons here in the US who all work in different OI clinics around the country, talking more about this issue, about orthopedic care during this pandemic, and sort of what happens if you have an orthopedic concern, a fracture or something else that is not directly COVID-19-related, but because of our times, it all is.

So, a quick plug on that. We sent out -- it's in the same email. You probably got a message about this. That will be happening in a few hours at 5:30 eastern standard time in the United States.

I want to go on to some other questions that we have. So, this is actually from someone who is I see on the call with us, Ingan, and she works with the OIFE over in Europe. She is asking, I see there are many volunteers from OI organizations here. What can the organization do to help our members in this situation, beyond these webinars? So that is actually a question too. I think this is a great question. I think this is to Michelle and Kara. What were some things that, you know, you would like us to see doing more of?

>> Dr. Ayers: I think we are learning so many things to put kind of in our back pockets, right, of okay, we need to address this, because so many of us never saw these different things and how they would play out. So in some ways, I think we are adding to our list of what we can do in the future to be covered and prepared, but there are also some things that we can do in the moment. So I think we can do two things at once, right? So we can benefit from our OI specific connections in the community, while also realizing that we are a part of this larger cross disability community, too, so our OI specific organizations can take part in some of the work that's being done to advocate for civil rights for people with disabilities, and we can think through the ramifications of the policies that are being discussed, so from the rationing of supplies or resources to also some of the visitation policies. If people live in care facilities, we are understanding the need and logic to do things like shutting down all visitation. In some places, residents aren't allowed to leave their rooms, but that isolation level has impacts on people, and these places often don't have capabilities like we have, today connecting to Zoom. So I think we can expect both. We can expect for the OI community to come together in our own little circle, but also realize that we don't want to miss these other connections in a broader sense that are happening too and need to continue to happen, even after we are out of the main risk of this.

>> Dr. Fynan: Definitely, and I think having opportunities for members to be heard is ultimately what's so important, something that Ingunn said was, you know, except for these kind of webinars, what can we do as an organization? And I really just want to circle back and kind of plug the person-centered outcomes research, that we won a grant for, and it really is a wonderful opportunity for people with OI to be heard. It's being requested of us to share what do you want research to be about. It's not the

doctor sitting in a room, saying, you know, "I'm really interested in this one thing." It's people with OI having an opportunity to share concerns. So, I would just encourage everyone to get involved, for sure.

>> Michael Stewart: Great, thank you so much. I very much appreciate that.

So, I'm going to keep moving on to other questions we have received. This is about breathing. Do you have any advice on how to understand if our breathing issue is due to anxiety or panic attack, or it is for other reasons?

>> Dr. Fynan: I can start with that one. I think this kind of goes -- this speaks to why it's so important for us to start not only being aware of the tools that we have available to us, when it comes to managing our anxiety, but it also speaks to the importance of just understanding and listening to your body. The mind-body connection, phew, and the body will tell us what the mind forgets, because our mind is a very powerful thing, and we are able to kind of push a lot of stuff away, as far as when it's traumatic, but your body will remind you, and having, you know, rapid breathing and just having chest pains and things like that, where -- how can you tell if you are actually having, you know, respiratory distress or if it's panic? So, I think a really great way to get started is to start keeping track and start journaling of when these things happen, kind of sit and think about am I sitting here watching the news when it's happening, am I sitting here, you know, ruminating about something? Is there a direct trigger? Because we want to be able to identify the triggers so that we aren't surrounding ourselves with things that trigger anxiety, which triggers rapid breath, which then triggers our anxiety. It's a cycle.

And then, so if we are tracking our symptoms, just to kind of become aware of them, also testing out some of these tools that we talked about today, reframing our negative thoughts, doing some gratitude journaling, and, again, these things might not feel authentic to you in the beginning, but I do encourage you to test a number of them and see what resonates most with you.

And, of course, if you really are not feeling okay, if it is something out of the ordinary, then you do want to reach out and call your doctor.

Kara?

>> Dr. Ayers: Yeah, I would really echo what you said, and I really picked up on the cycle part that you just illustrated there with the -- so, again, it may not be either or. It could be both, but I think it's also important to really consider what your baseline was, and this is yet another reminder of if you didn't really know your baseline before this, it's another thing to put down that maybe, you know, in a few months when this hopefully has passed, that you may want to make a visit if you haven't yet with a pulmonologist or get an idea of what is your baseline for lung health, because it's going to vary for all of us. But I think overall, it's just such a time for self-reflection, and life in a lot of ways for some of us has really slowed down, so it gives us that space, but sometimes that space can also be filled by some of these triggers as well.

>> Dr. Fynan: Right, and when there is opportunity for self-reflection, especially if you're the type who one of your coping skills is completely filling your plate so that you don't have to feel or think or reflect, now some of the things that filled your plate once before are no longer on your plate, and you're being faced with some of these feelings, right? So, I think it is important now, more than ever, and it's an opportunity, now more than ever, and I -- you know, full transparency, I am recognizing that for myself, that, okay, Michelle, you have got to feel it to heal it, girlfriend. So, you know, we are all in this

boat, and we are all in different areas on the continuum of coping and dealing with things, and I just think it's important to support each other through it.

>> Dr. Ayers: Yeah.

>> Michael Stewart: Great, thank you so much.

Another question we have, any tips on how to deal with the unknown? My two and a half-year-old son has OI, and I can't imagine self-isolating until there is a vaccine. I'm trying to take it one step at a time, but every now and then, there are questions of what will life look like moving forward, and they keep creeping in.

>> Dr. Ayers: Yeah, I think this uncertainty piece is -- so we know that that in itself is a huge trigger for anxiety, and usually the metaphor that I use for people with anxiety is, when I'm discussing anxiety, is that anxiety is somewhat like a fire, and so if we continue to avoid and continue to avoid thinking about it or doing anything about it, and we are putting accelerant on that fire, we are really making it worse. So we need to approach whatever we are thinking about, talk about it and think about it, but in many cases with COVID-19 and the response to it, we don't even know what we are approaching, because we don't know; is it weeks? Is it months? I know similar to this individual's question, a related fear that I have, is right now, for the most part -- and at least, yes, I can only speak for my state and my community, at least we are all kind of on the same page of treating this as if we need to be cautious across the board.

One fear that I have is that there's differing levels of this, and people who don't consider themselves to be high risk and return to work and schools are back open, I have three kids that are expected to go to school, so I worry about a stratification of where we'll be needing to make decisions about isolating, and not everyone else is anymore.

So, but I think one of the things that I have to do, when I go down these paths, and it feels kind of like a train out of control, and I almost just have to stop myself on the tracks and recognize that none of this is certain, and I am not getting anywhere by thinking of all of these what ifs and when will there be a vaccine. So I especially, personally, have to do this at night, because I'm a completely irrational person at night [laughter] and when I wake up in the middle of the night and I start thinking about these things, it just can become a runaway train, and I personally don't find anything for myself positive that comes out of it, so I do have to use thought stopping techniques, whatever they may be. Some of them again are somewhat artificial, and you might make yourself think of an animal, every time you have that thought, get yourself off it. Think of a color, a different color. It really helps shift your brain from that runaway train track. It's so uncertain right now. There's not much we can do to really figure out our way out of this.

>> Dr. Fynan: Right, and I think that for the parents, since the person asking this question was a parent, you know, it's -- when you're also considering someone else, when you're considering your little one and not just worrying about yourself, too, it can add another layer to the anxiety, and I think, too, I don't know if the parent is familiar with OI or if this is like a new thing on top of a new thing. Like, maybe OI was also the new roller coaster that you hopped on just recently, with it being your child only being two, and now we are dealing with another thing of uncertainty. So, but, really, I think that we deal as humans with uncertainty quite often. We like to think we have a lot more control than we

probably do, and I think just kind of sitting with that, recognizing that we can really only control ourselves, we can really only control our thoughts, and at times they feel out of control, like Kara was saying. And I can definitely joke about how I was like, you know, I better get myself together before I go talk about mental health and anxiety for everyone, you know, because just to be real, we are all human, right? But some of us have an educational knowledge, and then not only educational knowledge, but experience of putting these tools to work.

So, if you're just now kind of looking at these tools for the first time, find whatever you can to support you in your educational journey and find a support group. Find other moms or parents who will do Zoom dates with you, with your kids. Find different ways to connect again, because the more you feel connected in some way, the better you will feel about navigating the uncertainty.

>> Michael Stewart: Great, thank you so much. So we are getting some more questions into our chat feature as well.

One question we have is should we limit the time watching scary news or social media during this time?

>> Dr. Fynan: I think that depends for yourself. It's going to be, like Kara said, some people are comforted by hearing facts and information, but, again, facts -- like, we really have to make sure that the sources that we are choosing to pay attention to, that they are sources that we feel good about. So, but for myself, I will say, I, in the beginning, the researcher in me wanted to read, read, read, read, read, get all types of information. I want this perspective, I want that one, and that's when I noticed my anxiety was through the roof, and I had to put my own boundary. And everyone's boundary is going to look different, but I would say find what works for you to where you can feel educated and prepared, but also not inundated with fear.

>> Michael Stewart: Thank you.

>> Dr. Ayers: I would say the same. I think you have got to find your own balance for that, where you feel informed but not overwhelmed, and it may change. Some days, you may be able to handle it, handle a bunch of stuff; other days, you may need to unplug completely.

And what I have found is enough people and places are repeating things that you'll hear eventually, if you need to. So, you'll get your information.

>> Dr. Fynan: Yeah.

>> Michael Stewart: Great, thank you so much.

So, we are getting a couple of questions from people about dealing with self-isolating in children and how to manage their fears. I see we have one question from an attendee from Peru, talking about seeing soldiers in the street and how very understandably, that is scary, and how to deal with children and if they are having nightmares in regards to that.

We are getting other questions about how to just talk to your children about this overall, and I was wondering if you two would be willing to sort of talk about that general theme, of how do you both discuss this and also help support your children during this time.

>> Dr. Ayers: Uh-huh, yeah. So it is a scary time for kids, and they don't, you know, have the same interest or opportunity to kind of take in some of the information that we have had to explain. I think what's really important, and I'm working with the American Psychological Association to tie some of the research that we have about how kids understand crises like this and how we can help them best know what they need to know but also not give them so much information that they are afraid, and I'll share that with the OI community when it's finished, but one of the things that we have decided is not to avoid with kids talking about it, so I'm not so scared that I'm not going to mention words like coronavirus or COVID-19. First of all, if your kids are in school at all, I would say even in preschools in some cases, they have heard it. Their peers are talking about it, and they may have been talking about it, in our case, a few days before school shut down. So it's really important that you do talk with them about it.

I have really liked a lot of the materials that are actually developed for kids with autism. They are called social stories, but they are useful for anybody, because what they are is simple text that explain some of these things, and then they have some picture icons. So it allows you to help kids see it while you're talking about it, and it gives them an opportunity to see that other families are talking about this. You know, there's no real way to normalize this. It is scary, and you need to validate that, and then you need to realize, too, that kids kind of take pieces that you give them and apply them in different ways, and so you can't just have like one talk about it and be done. An example of that is last night my family and I were taking a walk, and we were happy to finally get outside and in the sunshine, and I kept asking my son, who is 12, questions, and he wasn't answering. So I said, Eli, why aren't you answering? He pointed to his mouth and said, "I'm holding my breath so I won't breathe in the virus." It's like, no, we don't have to hold our breath the whole time we are taking this walk, but, you know, he had heard a lot of dialogue about how it could be in the air. So he had a fear that we needed to address. You know, my nine-year-old had heard too that we can't touch our packages on the porch, and so we talked about how we can be safe about that, and we need to wash our hands. So just like us, they want to know what they can in the situation. They like to feel like they are safe, that we are taking care of what we can take care of. But there are an increasing number of age-appropriate resources that you can share with them. I just shared the link in the chat box to Sesame Street Kids, a workshop that is research based that I like, and a lot of times they come out with different language options, which I like as well.

>> Michael Stewart: Great.

>> Dr. Fynan: That's awesome, yeah, and in addition to those, just to kind of piggyback on the avoidance of talking, versus how do I know how much to share with them, kids, whether or not you're saying something audibly, they are picking up on your energy, and if you are stressing, it can be helpful for them to understand that something is going on, by you communicating that to them, because if not, they may be still receptive of something is going on, but I don't know what. I think also being -- being kind to ourselves, being kind to them if they are reacting a little bit differently, maybe personality-wise having those mood changes, like we talked about for ourselves, recognizing how we are handling the stress and then also recognizing how they are too, and checking in with them and asking questions.

>> Michael Stewart: Great, thank you so much.

So, this has been for me incredibly informative and also a calming presence, so I want to thank you both so much. I want to take this time to project, actually, from my screen a slide that we had projected in our last session. So if you guys don't mind me for one moment, as I project this, so, we have been

noticing that we are getting a couple of questions that focus more on the medical side of dealing with COVID-19 and OI. Unfortunately, on this call and on all of our calls, we are not practicing telemedicine, so we will not -- we unfortunately cannot answer direct medical questions. However, if you do have questions about OI and COVID-19 overall, I would please -- one moment. I want to just make this go full screen. I want to recommend everyone go to [OIF.org/coronavirus2019](https://oif.org/coronavirus2019). This is also linked directly to on our web page, [OIF.org](https://oif.org), and if you want to reach OIF, you can reach us directly at BoneLink@oif.org. You can also call us on those two numbers below. However, obviously, so we are not at the office physically until further notice, so I believe that the most direct way to reach out to us is through our email. Again, if you have questions that are not answered in this session or that are more specific to you, we are happy to talk to you, and please check out that web page, OIF coronavirus 2019. We are going to be posting all of our updates there. I'm going to stop my share right now.

And I see that Kara and Michelle have already posted some links as well, about PCOR, about the Sesame Street as well.

Kara and Michelle, do you have any final words you want to give before we sign off?

>> Dr. Ayers: Yeah. I have one that I have been trying to focus on. It's kind of my affirmation right now, is that, you know, our world definitely is turned upside down from this, and a lot of things have changed, and I have heard people saying it will never be the same, and, you know, maybe that's true, but maybe also in a positive way. And I'm thinking of how many creative ways that the rest of the world has figured out to make things work, when you can't necessarily get out and about like you used to, and how many ways that could benefit our community and that we are contributing to that, too. We are saying, you know, we can work like this, we can work like that. One example is how many of us successfully figured out how to telework and how many people with OI said I can do this job amazingly, but I can't get there because I can't drive or I can't get there every day because of my pain. So the world may be different from here on out, but maybe that won't be all negative.

So I'm looking forward to it and trying to keep my focus on staying healthy and being helpful.

>> Dr. Fynan: This, this, 100 times this. And that's been my focus here of how are these creative solutions going to benefit our community so much. So, let's keep contributing to those, and let's keep connecting. Let's keep doing these things. Let's meet outside of here, you know, and stay in touch with one another and just support one another through this.

>> Michael Stewart: Great. Thank you all so much for joining us, and just one last quick plug, we'll be having another session today at 5:30 p.m. eastern standard time on orthopedic perspectives on this changing pandemic and how to deal with your OI care during this time. Again, thank you all for joining us. Thank you, Kara. Thank you, Michelle, and hopefully we'll see you soon. Stay healthy, everyone, and good-bye.

(End of session.)