

Caring For the Caregiver During a Pandemic

Webinar Transcript

Krista Davis: Good afternoon, and welcome to today's webinar, Caring For the Caregiver During a Pandemic. My name is Krista Davis, and I'm a Communication Specialist at Quality Insights and your host for today's presentation.

Krista Davis: We'll get started in just a few moments. But first, a few housekeeping items. All participants entered today's webinar in a listen-only mode. Should you have a question or a comment during today's call, we ask that you please type it into either the chat or the Q&A box to the right of your screen. If you're unable to locate your chat box, hover over the bottom of your screen and click the circle with the speech bubble.

Krista Davis: The slides you see today were emailed to everyone who had registered earlier this morning. They will also be posted on our website before close of business today. You can find the web address in the chat box.

Krista Davis: At the end of today's program, you'll be asked to complete a short evaluation. This evaluation will help tell us how we did during this program and how we can help you during this challenging time.

Krista Davis: Today you'll be hearing from JT Hunter, President and CEO of REMT Care Partner Coaching & Consulting, LLC. But first I'm going to turn the program over to Quality Insights, QIN-QIO Program Director, Bidy Smith. Bidy.

Bidy Smith: Hello. Thank you Krista, and thank you all for taking time out of what I'm sure is a hectic day to join us. I'm Bidy Smith with Quality Insights, and I speak for everyone here when I say we hope you're able to learn something over the next 30 minutes that is valuable to your work. For those who may not know, Quality Insights is the quality innovation network, quality improvement organization for Pennsylvania and West Virginia. We offer a network of peer support, technical assistance and education on timely topics that are important to you.

Bidy Smith: Next slide.

Bidy Smith: Currently our QIN-QIO work is focused within two learning and action networks, Nursing Home Quality Improvement, which is focusing on infection prevention, five star improvement, medication safety and reducing the hospital admissions and readmissions.

Bidy Smith: Next slide.

Biddy Smith: Community Coalitions' quality improvement work is focusing on behavioral health, improving patient safety, increasing chronic disease self management, decreasing avoidable emergency department visits and medication safety.

Biddy Smith: Next slide.

Biddy Smith: If you value just-in-time presentation such as the one when you're about to hear and having a network of peer support and readily available technical assistance and resources, then please take two minutes during this call to join us. The link can be found in the chat box.

Biddy Smith: Next slide.

Biddy Smith: Now it's my pleasure to introduce today's speaker, John T or JT Hunter. He is the President and CEO of REMT Care Partner Coaching in Charleston, West Virginia. JT provides meditation, education, coaching and support for family and professional caregivers. He was the 2019 president and is the current secretary treasurer of the West Virginia Geriatric Society. The floor is yours, JT.

JT Hunter: Thank you very much Biddy, and thank you all for having me. I'm honored to be here today.

JT Hunter: Next slide please.

JT Hunter: So this is how we may feel right now and what the world looks like to us. There's so much fear and uncertainty around the world right now given the coronavirus situation. People all over are trying to deal with this in different ways. So how can we be as calm and happy as we can be under these circumstances? Sometimes people assume that happiness means being 100% happy 100% of the time, and that's just not possible. That's not the reality. But let's face it, there are times when we don't feel happy or calm, and that's perfectly appropriate and natural. But even in those times, we can take steps to feel as happy and as calm as we can and in doing so, we can not only help ourselves weather a crisis more effectively, but at the same time strengthening ourselves to be more helpful to others in our communities.

JT Hunter: Next slide please.

JT Hunter: So does it feel like all eyes are on you right now? Everyone's watching? And here are some facts. The first deaths reported were in a nursing home. You care for the most vulnerable people to this illness. And also CDC, some other health-related organizations are suggesting that the families of your residents contact you to check on their family members. Let's be very honest, there are some families, caregivers that may even resent and not understand your new restrictions right now.

JT Hunter: Next slide please.

JT Hunter: So here's how I see it. Right now, you are the brave mouse, and at times you may even feel more like the crazy straw. Getting the job done, but at times maybe feeling all over, up and down. Or to even be more honest, maybe at times you even feel like the turtle.

JT Hunter: Next slide please.

JT Hunter: A part to this, one important part of dealing with your own stress, is trying to put yourself in the family's shoes. Helping staff understand how the family feels can also help them. So let's take a moment and look at some of those concerns from family caregivers just like Mrs. Johnson. Mrs. Johnson is a spousal caregiver for her husband who has frontotemporal dementia. And you can see on the slide, on March 11 didn't make her Saturday trip and doesn't know when she'll be able to return. And her concerns are things like, "He won't let anyone clip his fingernails or shave him besides me." And she also addresses the timing is so hard because just like so many, she wants to be there more frequently because of the decline of the disease. But also her reality is that it's impossible for her to do it the way she wants to. And she even adds to that concern to say it's really scary to have this out there when you have someone who doesn't know how to be sanitary and is incontinent.

JT Hunter: Other caregivers, for instance, worry because they assist the staff with care. It is a partnership. At many, many times we have wives feeding husbands, husbands making sure their spouses do their physical therapy. Social isolation and depression can become big worries. One of the most frightening things for family caregivers has just come to life. So many caregivers feel like Mrs. Johnson, and our worst fear as caregivers is not being able to get to our loved one. We carry that burden so often of being the quote ... I'm using my hand quotes ... "The only one that can or knows how to do that thing the right way."

JT Hunter: Next slide please.

JT Hunter: So here's the good and bad news. Other organizations may be encouraging families to call and ask about things like teleconferencing. However, if we look at that for example, with a reframed outlook, this also gives you the opportunity to possibly strengthen and build those relationships with those families. Now let me say this. Yes, communication is key. The cell phone, for example, could be helpful, but it also could cause more stress. So not telling you what to do, but planting the seed of thinking differently than we than did before.

JT Hunter: The overall message is this. There must be contact and communication between us and the families. We know that. As a coach, I will share this. It won't be perfect, but our goal during this time should be more focusing on good enough,

finding ways to let families and caregivers know the person for whom they care for is loved, safe, secure, and as content as possible.

JT Hunter: And yes, we may need to think outside of that box. And here are just a few examples of some ways to accomplish the goals for care and for those families. So I hope this helps, and we've probably all see things over Facebook and the internet lately, some brilliant creative ideas. Thinking outside of that box and remember getting creative. How can we continue the best we can to try to instill that environment, that calming, safe, happy-as-we-can-be environment for those people we care for.

JT Hunter: Next slide please.

JT Hunter: But you also have concerns and worries. Let's talk about you all for a moment. Bravery is not the absence of fear. Bravery is feeling the fear, the doubt, the insecurity and deciding something else is more important.

JT Hunter: You are the epitome of bravery. Not all superheroes wear capes. Thank you. But you're also human. Your moms, your dads, sons, daughters, some personal caregivers, you have other people that care for and need you. And in many aspects you have the same worries as every other parent, friend, neighbor out there. However, added into that, you don't have the option to socially isolate as so many others do right now.

JT Hunter: I'd like to share this text from a caregiver in a nursing home that's one of the most affected right now in West Virginia.

JT Hunter: "News for tonight. I'm going to punch anyone who says we signed up for this because we worked in healthcare. No one could have dreamt the horror that is going on right now. Residents are sick and sad. Families are worried to death, and staff is exhausted, especially the nurses who are working double shifts. 59-year-old fat me was pushing six residents in bed, and trust me, almost everyone was doing even more. The worst thing for me of course, is not being able to see or help my mother. At some point if this lasts for much longer, I may have to quit. The community's being good to us in some ways, sewing masks, sending pizza. But not so good in other ways. Stores not wanting us to come in. Employers of spouses closing and blaming us. Anyway, physically I am okay. Mentally I go from okay to a complete mess. The worker bees here are amazing. When one of us is ready to lose it, another finds strength to pick us up. We are sharing an experience that has brought us closer than ever. Anyway, love you all. Thanks for checking on me and praying. I need you."

JT Hunter: So there's a lot going on right now and many of you, I'm sure, can relate to what I just read. And this is the reality of what we're going through. So there's a lot on our minds, from the lack of equipment to the views from others in the community and us just trying to survive.

JT Hunter: Next slide please.

JT Hunter: So today I wanted to bring you some quick tips to put in your toolbox, some tools that you can use and that are quick and simple and easy and things that we can adapt with wherever we are, however much time we have. So I'm glad you received these slides, and please carry this with you. So I'm not going to read everything on here, but I do want to make some points.

JT Hunter: So staying informed, but being aware of information overload is very important right now. We all want to stay up-to-date with the latest news, but it's easy to get overwhelmed. So consider scheduling that time to check current events. Maybe twice a day so it doesn't overtake you.

JT Hunter: Try to find reliable sources. We all know there's a lot of unreliable info out there. As best we can ... We all know a negative Nancy ... When I coach people I talk about trying to draw that circle. If it's helpful and good for you, absorb it. If it's not, try to set parameters. Schedule that time to worry. Surprising, but it's very effective. So try saying to yourself, "I'm going to worry for the next 10 minutes." Then move on. And remember the goal here is not to not worry, but to help you not to get stuck in the worry. And reframing ... I mentioned this earlier ... For example, instead of thinking this is a very inconvenient time, a possible way to reframe that thought is, "This is forcing us to be more creative." This tool reframing, it can take time and practice, but it can be very effective as well.

JT Hunter: Next slide please.

JT Hunter: So keeping a journal I thought was important, and I reflected on conversations with loved ones and my great grandmother who talked about milestones in her lifetime. I'm not saying this is going to be one we're going to reflect on and look back with joyous memories, but it is a milestone in the life of the world. And when it is all over ... At some point it will be over ... We may be glad we kept that record to reflect on and look back on it. Hopefully look at it and say, "We survived that," and learned from it.

JT Hunter: Connecting with others. In this day and age with technology, iPhones, texting, I've seen amazing things on Facebook. Once again we're getting creative, but the overall goal is that human contact. It may be a text, it may be a quick phone call. It may be sending a meme or a picture to someone you care about just to bring a smile to their face. This is not only helping us, but it also may be spreading joy and a smile to others out there affected by this as well.

JT Hunter: And of course, eating healthy. If you're like me when I'm stressed, when I'm overloaded, when I'm anxious, I'm not always thinking about eating apples and vegetables. So doing my job, it's very important to remind us that typically too

much caffeine, too much sugar and other unhealthy foods don't help the situation. Could cause other issues.

JT Hunter: And the water. Drinking water is very important. It does so much to the body. It help cleanses. It can help with our stress levels. Very important. Again, keep in mind we're going to have cheat days. Sometimes it is whatever we can get our hands on, but I just want to stress that point. Eating healthy is also important.

JT Hunter: Next slide please.

JT Hunter: Taking breaks when we can. They don't have to be 30 minutes or an hour. We could break them down into five-minute periods where we're taking that break. Scheduling again, just like with looking at the news, finding that time to make sure we're taking a break. Remind yourself that this is not forever.

JT Hunter: And deep breathing. I wanted to list this here on the slide so you can take it and use it anytime. It's very effective. It is very simple in context, but it can make a difference. It helps us center, and this again is something that's portable, adaptable, something you can take and utilize wherever you are, whatever the limit of time you have is.

JT Hunter: Next slide please.

JT Hunter: Staying at your best. Again, tips to adapt and adjust. When you do go home, try to make time for that few minutes of an activity you love. Here's the thing. Right now, we may have to think about how to adapt and adjust. We work a lot with caregivers and care partners who want to keep an activity and something the person they care for loves in their lives. We talk about how to explore. Oftentimes getting creative to find those ways that they can possibly match that sensation in a different way than they did before. So I wanted to list an example of that here. This is also a tool that we can use in our life now.

JT Hunter: Trying some healthy exercises. Watch YouTube videos for great ideas and there's exercise apps. And once again with the technology, there's many ways to have this at your fingertips, especially when you may not have a lot of time.

JT Hunter: Next slide please.

JT Hunter: So yes, doing my job, I have to mention the sleep and some of you may be rolling your eyes. I understand, but it's important to talk about. It is important to our bodily function and how we feel and our stress levels. So once again, as a coach, just reminding you when you get home, maybe that's not the time scheduled to worry. And remember bedtime did not worry time. Trying to create a routine just like we do with our children when they were very small. Create one for yourself. Use the breathing idea again anytime or maybe imagine a movie in your mind or watch a movie that makes you laugh. Also, just wanted

to mention melatonin may help as well, but not leave you so groggy in the morning.

JT Hunter: Next slide please.

JT Hunter: So thinking of all the resources and organizations and information I wanted to bring, I had to narrow it down. So I thought just given the situation and my main focus as being caregivers and the adult population, I wanted to throw some helpful resources that help you with the coronavirus, how to talk about it with elder family members, but also children, teens. And as you can see as you look on this slide, you may see a lady, Gretchen Rubin. Her website has amazing podcasts for the healthy spirit, ideas and tips like ways to stay calm and reduce your anxiety during the coronavirus times. Mental health is very important as well. Whether it's yourself, someone you care for, always knowing who and where you can reach out to. I want to make sure you have these resources. And this is just a blip on that big radar of all resources out there.

JT Hunter: Next slide please.

JT Hunter: A couple organizations I want to quickly mention. In West Virginia, especially highest population of the elderly and AARP is a national resource but has amazing resources and information on their website. And you can also give them a call to get connected and find out how you can help the person you care for or yourself.

JT Hunter: The Alzheimer's Association, amazing resource, has a 24-hour helpline that you can call, caregivers can call and get questions answered. It helps you look for resources. Maybe just listen ... and I want to stress this ... This is not just for families. Professionals, you can call that helpline as well and get connected. Whether it's venting, whether it's strategies, whether it's, "I'm just alone and need a person to talk to." Anytime. 24/7.

JT Hunter: American Diabetes Association. Again, in West Virginia especially, diabetes is ... West Virginia is number one in diabetes per capita, and we know the effects and those things that diabetes can do with other illnesses and how it can propel or make it harder to fight them. So it's important.

JT Hunter: Family Caregiving Alliance. Very important resource to know about. And once again, this is just a small blip on that radar, but I want you all to know about these things and know they exist and please share them. There is another resource page that you probably got emailed or is on Quality Insights' website. Again, just spread that information. It's a starting point. Some of them No Wrong Door of Entry. Spread and share that information.

JT Hunter: Next slide please.

JT Hunter: I want to leave you with this. My job once again is to provide education, enlightenment, empowerment to all people out there who care for someone with Alzheimer's or related dementia. And I thought this was a great way to end this. So the quote says, and I'll read it if you can't. It's a little blurry maybe. The quote says, "There are dark clouds," said the boy. "Yes, but they will move on," said the horse. "The blue sky above never leaves." Once again, I can't thank you enough for what you're doing. Thank you for being here today and listening, and I hope this helps.

Krista Davis: Thank you very much JT, and once again if you have any questions in the time that we have left, we invite you to please type them into the chat box or the Q&A box on the right side of your screen. We'll get to as many as we can in the next seven or so minutes. And if there are some questions left over at the end that we do not get to, we'll address those in an alternate fashion via email following the conclusion of this program.

Krista Davis: So we'll get started with some of the questions that have come in while you've been speaking, JT. The first one is just kind of a blanket question and that was, is anyone dealing with grandparents raising grandchildren and then the grand gets diagnosed with COVID-19? Who is going to take care of the grand and who is going to take care of the grandchildren? Do you know of any resources or plans to help with this?

JT Hunter: Great question. A big concern, absolutely, for all of us, and again, especially being here in West Virginia. I do know some organizations that are addressing the issue and trying to help the grandparents raising grandchildren. One, for example again, AARP works very closely with families and other community organizations that are trying to provide resources and support for them. But also in that question, you bring up an excellent point. Here's the reality. People at the higher risk factor, age risk factor, may also be caring for young children and they need resources. So right now, just quickly are United Way, AARP, Faith in Action, organizations in the West Virginia community that are ... Again, it's a partnership ... It's team banding together. And once again, the way we look at it is, I may not have everything, but I may have a small piece.

JT Hunter: You may have a small piece. So really what I'm seeing in West Virginia and especially in Kanawha County where I'm focused is we're talking to each other. We're connecting with each other and sharing. So hopefully it may take a village, and I apologize if I couldn't give you more specific names on this call, but we are trying to band together and that's what we found. We can't do it alone, and that is the reality of where we are. So we need to be thinking and getting creative on ways to make sure they're supported.

Krista Davis: Thank you. And our next question is regarding the tips that you gave for we, the caregivers, would it be good for us to share those with our residents and our patients as well to help them too? Are they applicable to them as well?

JT Hunter: Absolutely. Absolutely. When we're talking about residents of course it depends on their level, their capacities, the disease they're dealing with. But absolutely, there may be something in there or the way you present it that can help them. I talk about this a lot. People with dementia especially, don't forget they have concerns and issues and worries and helping them find ways to address it, deal with it and handle it. And some of these tips for example, may be in the moment something we can do together and help in that moment, and we may need to do it again. And then on the other side, I think right now families are really struggling, feeling helpless. And not only feeling helpless that they maybe can't do what they want to do for their loved ones. They care about you all in these facilities too. You all become families. I was a caregiver for a decade. I can tell you, you become part of my family. So absolutely, that could be another thing we're giving to our families at this time and empowering them. Absolutely.

Krista Davis: Thank you. And I am just ... I had one more. Just one minute. Oh, okay. Then the last question that I see at the moment is, I feel like I just don't know how to begin. How to even start to take care of myself. Can you give me a good starting place so that I can start taking care of myself and then take care of my patients?

JT Hunter: Yeah. I'm going to be honest. When I work with caregivers ... And I think there's some similarity in the situation ... Sometimes first we have to deal with the emotions and address that and talk about it. So I'm going to put out there first of all, it may take talking to someone in a safe place with no judgment, to be able to say, "I'm mad. I'm scared, I hate this. I don't like this person." You may need to share that in a safe place to help you feel strong enough to see the benefit in trying. But let me also throw this out there. A lot of us as caregivers, professional and families, get lost in that track of it's about them. It's not about us, and we get lost in that mud. So as weird as this may sound, I'm going to say I would encourage that person to reach out and talk to someone.

JT Hunter: It may be the Alzheimer's Association where it can be private at four in the morning, if that's what she decides, to first talk about her fears and her emotions. That may help her feel a little normalization and then be able to work. It takes practice. So whatever tip you try, I would say pick one. Maybe it's watching funny videos for two minutes a day and you start small and you build up steps. But I guarantee, I think whatever you try first, you'll see a benefit and that excels us to want to have it again. So I think we start small, but be realistic. Face those emotions and share them. Find your outlet and then you may be strong enough to try one of these tips.

Krista Davis: Great. Thank you. There are no further questions in our queue at the moment, so I'm going to turn things back over to Bidy Smith for some closing remarks. Bidy.

Bidy Smith: Thanks Krista. Again, thank you JT. I think this has been so impactful and just really what we need to hear it in this moment of chaos. So I really appreciate your time. I want to thank everybody on the phone for joining us for the

webinar. I would ask you to please take time and fill out the evaluation. If there's topics you would like for us to present on, please let us know. That's what we're here for.

Biddy Smith:

Remember, we're here to help. Krista, if you'll put up the last slide. On the screen, you'll see some contact information if you want to reach out to us on a more private note, please feel free to email us. We're here to help. Thank you again for your time. We appreciate everybody's hard work. Hope to talk to you all soon. Thanks.

This material was prepared by Quality Insights, the Medicare Quality Innovation Network-Quality Improvement Organization for West Virginia, Pennsylvania, Delaware, New Jersey and Louisiana under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. Publication number 12SOW-QI-CC-032720