



Kessler Foundation Podcast Transcript:

Caregiving for Persons with Traumatic Brain Injury while Sheltering in Place for COVID-19

Recorded April 2020

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NANCY
CHIARAVALLOTI: 00:06 [music] The better the person with the brain injury functions, the better the entire household can function.

ANNOUNCER: 00:12 Caregiving for persons with traumatic brain injury while sheltering in place for Covid-19. Caregiving for a loved one who has experienced a traumatic brain injury can be stressful in the best of times, let alone, during a pandemic. In this podcast, Dr. Erica Weber hosts a conversation about traumatic brain injury caregiving in the time of Covid-19 with experts from Kessler Foundation. Listen in as Dr. Weber introduces our guests.

ERICA WEBER: 00:43 Hi, and welcome to the next segment of our podcast series focused on critical issues faced by the disability community in the times of Covid-19. I am Dr. Erica Weber, a research scientist in the Center for Traumatic Brain Injury Research here at Kessler Foundation. And I'm joined today by two of my colleagues for a conversation on caregiving for a loved one with a traumatic brain injury while under stay-at-home orders. So I'm here with Dr. Nancy Chiaravalloti, who is the director of the Center for Traumatic Brain Injury Research at Kessler Foundation, as well as the director for the Center for Neuropsychology and Neuroscience Research, as well as Dr. Denise Krch, who is a research scientist in the Center for TBI Research, and she is currently conducting research on supports for TBI caregivers. So thanks to you both for joining us today.

CHIARAVALLOTI: 01:29 Happy to be here.

KRCH: 01:29 Thanks for having me.

WEBER: 01:31 Sure. So to start off, Dr. Chiaravalloti, could you lay a foundation for us of what is a traumatic brain injury and how does it affect the person and a system?

CHIARAVALLOTI: 01:41 So a traumatic brain injury is any injury to the brain that occurs as a result of an external force hitting the head. So it could be the result of a car accident or a fall or a sporting event. That's what a traumatic brain injury is. And traumatic brain injuries can be graded from being more mild in nature, similar to a concussion, to the very severe traumatic brain injuries where the person's life may be at risk when they're first injured. Traumatic brain injuries have a period of recovery and rehabilitation, and throughout that time, the person undergoes therapies to try to maximize their functioning. And we talk about rehabilitation as really being a lifelong endeavor after a traumatic brain injury because there are-- in the more moderate to injuries, there are deficits that a person is dealing with for the rest of their lives, and those deficits can have an impact on everyday functioning.

WEBER: 02:43 So this seems like something that is really going to be a longer-term issue that people are dealing with, not only the person with the TBI, but also the people in their lives



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who are maybe charged with helping them achieve their maximal functioning and living their best life possible.

CHIARAVALLOTI: 03:03

That's very true. A traumatic brain injury is something that someone is dealing with for the rest of their lives, and very often, it has a tremendous impact on the family and friends, particularly, in situations where assistance is necessary in order to carry out daily activities. And those situations, we talk about caregivers or care partners who are very involved in the person's everyday life and are really very, very important to how that person functions daily and how they're able to carry out their daily activities.

WEBER: 03:38

And now, Dr. Krch, so I know that you've been doing some research on this, and it's an interest of yours to know how being a caregiver of someone with a TBI is critical to that person and how it might really be a need of their own support systems. Can you tell us a little bit about what you've been working on and what you know about caregiving after a TBI?

KRCH: 04:07

There are a number of things that shift for a caregiver after their loved one goes through an injury and comes home, and there are changes in roles that happen as a matter of the injury. The coping skills that the individual had that may have been very effective for them prior to the injury may not be adequate after the loved one's injury when they're dealing with not only the demands placed on them previously such as continuing to maintain employment, but also taking on those added new responsibilities. So they may find that they need to look for and seek new ways to manage stress better.

WEBER: 04:54

That sounds like that would be a whole lot of juggling, both from a practical standpoint. I'm sure a lot of people can identify with the idea of not having enough hours in the day, but when all the sudden you're adding on new tasks. And then the emotional strain of having to cope with the fact that those tasks weren't really what you had been planning on doing. And not to mention, the stress of seeing your loved one change after a traumatic brain injury.

KRCH: 05:26

Yes. That's true. And often, the caregiver really just wants to maintain a good quality of life for both them and their loved one. So really, at the heart of all of this is this primary love for the survivor and wanting to make sure that they are reaching their maximum potential in life, but also maintaining a good quality of life for themselves. It's a really challenging time to make sure you're meeting those types of goals.

WEBER: 05:55

So with all of these new roles, it probably becomes very evident of what the person with the traumatic brain injury is maybe no longer as capable of. Dr. Chiaravalloti, could you give some insight into what types of problems people tend to have after a traumatic brain injury that does impact their everyday functioning?

CHIARAVALLOTI: 06:14

Following a traumatic brain injury, people who are impacted by the injury, the individuals that sustain injury is very often present with cognitive deficits, and those deficits have a substantial impact on their everyday life. So when I use the word cognitive deficit, what I'm referring to are all the skills that enable us to think and interact with our environment. So paying attention to a conversation or manipulating



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information in your mind. So as an example, if you're going shopping and you need to figure out what 20% off is, that's a cognitive manipulation. Remembering a new person's name when you meet someone for the first time or remembering to take medicine at a certain point in time, those are all cognitive tasks that we have to do every single day. So they're very reliant on our brains to be able to effectively carry out those procedures.

CHIARAVALLOTI: 07:09

When someone has a traumatic brain injury, those daily-life tasks can actually be very difficult, and that has a substantial impact on the home environment. So as an example, one of the major areas of cognitive dysfunction after traumatic brain injury is executive functioning. When I use the term executive functioning, I'm talking about organization, problem-solving, planning, all those things that you do every day to carry out household tasks. So someone with a traumatic brain injury that has an executive functioning deficit might have difficulty in a situation where they don't have a lot of structure. And in a home environment, that's very often the case. So they're not able to necessarily say, "Okay. Well, first, when I get up, I'm going to exercise, and then I'm going to have breakfast, and then I'm going to do some reading, and then I'm going to do work that I have to do for the day." They may not be able to do that, and that can have a substantial impact on their productivity for the day.

CHIARAVALLOTI: 08:16

So that's one area of deficit. Another area is memory. Memory is a major problem following traumatic brain injury. And if someone has trouble remembering things, that can have a substantial impact on how they're able to function in their daily environment, because in reality, we have to remember a lot of new information every single day.

WEBER: 08:34

Well, and what's really striking me about what you're saying with these cognitive deficits is that they may not be overly apparent to people who are, let's say, looking at the person in a store. They sound like they might fall under that category of having a "invisible disability" where it may not be as obvious. But to the person who is living with the person with the TBI, the change has got to be really noticeable, because these are our daily tasks that may not have given them a second thought and there may not be a change in the person's physical appearance or ability to walk. But really, these sorts of abilities you're talking about like memory and executive functions really permeate through everything that we expect to be able to do on a day-to-day basis.

CHIARAVALLOTI: 09:29

Absolutely. When you meet someone who has cognitive deficits, you very often don't know until you're involved in a longer conversation with that person, or maybe multiple conversations. So for someone on the outside who you meet for the first time, they may have absolutely no idea that the person is struggling with executive functioning or struggling with memory, but their care partner at home certainly does know. The people that live with them are very aware of the deficits, and they struggle to really help them function optimally in their daily life. Because the better the person with the brain injury functions, the better the entire household can function.

WEBER: 10:09

Absolutely. And Dr. Krch, I could only imagine that that discrepancy between what the person in the household, the caregiver sees, versus what other friends and family might see on the outside. That discrepancy might be a little bit difficult to manage



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when the person is first diagnosed and kind of beginning their journey. Can you tell us a bit more about how that might play out?

KRCH: 10:37

Caregivers are often faced with being at home, as Dr. Chiaravalloti mentioned earlier, that you often have to be in a conversation a little bit longer with an individual to notice that there might be some cognitive impairments going on. And the caregiver, by nature of being at home many more hours with this individual know very intimately what these areas of cognitive difficulties the survivor may have. And as a result, they have a difficult time communicating to people that aren't inside their home world what living with these challenges is like. And as a result, they may more and more either feel like others aren't understanding them, and because they don't feel understood, they withdrawal or they withdrawal just by nature of the fact that maybe some of these cognitive difficulties make it more challenging for the survivor and their caregiver to participate in social activities. So either way, you're looking at less time spent out in the community and more time spent in the home, and that social isolation can be actually one of the most challenging things that a caregiver was faced with.

KRCH: 11:58

In some of the prior research that I've done in the lab a few years ago, we collaborated with clinicians and rehabilitation counselors who work day in and day out with caregivers and their survivors and providing support services for those individuals. And in those consultations with these clinicians helping to inform our research, they've shared with us that really social isolation is one of the top three issues that caregivers struggle with most, and if not, the most challenging issue. So for this reason, caregivers then turn to when they can, actually, the brain injury community. And that's one great way to really reach out and feel understood and feel heard, because caregivers who are facing the same things in their homes understand the best what a caregiver is going through in their own home.

WEBER: 12:57

Absolutely. And thinking about social isolation, that's kind of what a lot of us feel like we're dealing with right now in this era of the Coronavirus and being asked to shelter in place and not being able to go out and use our usual social supports. So Dr. Krch, how do you think this pandemic is affecting those people who are caregivers for people with TBI?

KRCH: 13:26

I think there is both a positive side, actually, to this as well as is a downside. I think on a positive side, at least I think probably caregivers and their survivors were really faced, as I mentioned before with social isolation, from the time of the injury or not too long thereafter. And so social isolation is not a stranger to caregivers, so they have had to, over time, learn how to cope with that. So the social isolation that is now kind of affecting all of us in the Coronavirus pandemic is maybe happening more acutely, more rapidly, and so, therefore, is more traumatic for us. However, caregivers have been dealing with this a while. So if anything, they're very, very well-equipped. They kind of have already been living in a way a little bit more socially isolated than many of us have, and so they have probably developed really good coping skills because of that. But the social distancing does not have to-- it's synonymous with social isolation.



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- KRCH: 14:36 And I think even in scenarios where caregivers may have experienced a bit of social isolation, I'm sure that the social distancing that we're all being asked to practice right now is perhaps impacting them also in a negative way. So I really want to make sure that we think about the creative ways that we can social distance, at the same time, still maintaining our networks. In fact, even now, more than ever, caregivers need to access these tools that we can to stay in touch with people, to use social media, to use tools like Zoom to connect with their loved ones when they can't leave the house, to have a virtual meal with family members they might not be able to get together with. And to use all of those options that they have at their disposal to maintain connected during this time of social distancing.
- WEBER: 15:39 So a lot of the resources that I know caregivers have been using previously were based on in-person support groups. So for example, the Brain Injury Alliance of New Jersey, the BIANJ, had often used monthly support for meetings for their members. So Dr. Krch, do you know if they've been switching their platform to more virtual support groups now?
- KRCH: 16:05 Yes. That's an excellent point, Dr. Weber. There are a number of resources available online now. Things are shifting as most organization are shifting their activities from in-person activities to virtual activities. BIANJ is doing the same. Those support groups that they were providing in-person are now available via online platforms, and the link to those resources will be posted in association with this podcast.
- WEBER: 16:38 Perfect. Social distancing is definitely yielding some problems in terms of social connectedness, and it sounds like we're able to think creatively about how we're still scratching that itch and getting our needs met. But what do we think about how this is maybe changing the environment in the home? So for example, I could see scenarios where the primary caregiver for the person with the traumatic brain injury, their schedule might be changing, or now they're expected to do work remotely at home and have that interface with the person with the TBI's day-to-day schedule. So how do you think that they're being able to ask to juggle all of these different things?
- CHIARAVALLOTI: 17:26 I think what you raise is actually a very big issue in a lot of households right now. If you think about the typical environment post-traumatic brain injury - and this is someone who has a moderate to severe traumatic brain injury - the caregiver likely has to go out to work, because someone has to bring in an income. In this particular situation, the caregiver is not going out to work. They're working from home in many cases. In addition to that, when that person goes out to work, there is often some type of an aid, whether it's paid or unpaid, that comes into help the individual with the brain injury when needed. It might only be for meals. It might be for additional support beyond that. But very often, someone does come into the home to help out. It could be a relative. It could be a friend, or it could be someone who's hired. That individual is not coming into the home right now, yet, the caregiver still has to maintain both their work life as well as their home life and provide that assistance to their loved one. So that creates a very difficult situation for the caregiver, and it can be added stress.



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CHIARAVALLOTI: 18:37

So one of the things that I would suggest to help the caregiver deal with that is to create a schedule and to stick to that schedule. And this is partially to be able to fit the caregiver's work time into their family time, but it's also to help the person with the brain injury who might have executive deficits and who might need that external structure. So a schedule would provide that external structure. So perhaps, on Monday, you lay out a schedule for the week, and you say, "Okay. On Monday, we're going to get up. We're going to have breakfast. And then I'm going to go to work. I'm going to go do my work in the office or in the bedroom or in the living room, and the person with the brain injury will be doing this activity, whatever they do on a normal day." It could be anything that that person would normally engage in during their daily life. It could be reading. It could be doing work of their own. It could be watching a television show. Whatever that person can do to give the caregiver a chunk of time to be able to be productive for their work. And then, perhaps, that goes from 9:00 AM to 10:00 AM. Maybe they are able to extend it for two hours. Maybe it could go to 11:00 AM and they take a break. And they take a break together, and they have that written into the schedule, "Okay. Here's 20 minutes, and this is what we're going to do. And then we're going to go back to our separate activities, and then we'll meet in the kitchen for lunch. And at lunch, we're going to spend time together. We're going to put together the meal. We're going to have lunch, and then we'll go onto an afternoon activity." And providing that structure ahead of time can be very helpful both to the caregiver as well as to the individual with the brain injury, because it's providing a plan for the day, and it's something they can both count on. It's independent time as well as together time, and that's very necessary in this type of crisis.

WEBER: 20:38

And I like that because it allows for that level of predictability, and I think I can speak for a lot of folks right now saying that it's difficult not knowing how long this is all going to go on for. And needing some sense of predictability and stability as much as possible. So finding that even in a daily schedule. And especially for individuals with a traumatic brain injury who might not be able to process quite as well the reasoning behind all of these additional schedule changes and rules that are being enforced. So being able to have that as a pillar to stake your day around might really go very far in terms of reducing stress and anxiety around what's going to happen day-to-day. But I especially like that you brought in the idea of it's not necessarily using a schedule to maintain each individual person's activities, but it allows for specific areas of connectedness and just requires being a little bit more planful. But it allows that caregiver relationship to still remain positive and loving, and as you work to go through this experience together and that part of it is still we're getting together to enjoy a meal or to enjoy some downtime with the break and being able to make sure to budget that in so we're not just skipping out on those good times that we might not have had before.

CHIARAVALLOTI: 22:34

Absolutely. And those good times, those moments of social connectedness are so important right now. Their significance cannot be overemphasized. You need to have a period of time where you're together and able to enjoy each other, and that's much



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more likely to happen if you have a period of time where you're alone and you're able to accomplish what you need to accomplish in your daily life.

WEBER: 23:00

Absolutely. And Dr. Krch, what do you think about being able to connect with other caregivers? Is that something that you'd probably recommend getting written into that sort of daily schedule as well?

KRCH: 23:15

Certainly. Many people who have many caregivers who have participated in these in-person meetings have developed relationships with other caregivers in the community. And even in our own research, we've witnessed at the end of periods of time where groups of caregivers are convened for a support group. There has been this natural excitement about finding others with whom you connect, finding others who get you, who understand you, and it's been a spontaneous act where those caregivers have shared each other's contact information or remained in contact with each other long after that support group. So in the case where you're already connected with a community of other caregivers who maybe understand to a deep degree what the additional challenge of being a caregiver while social distancing, while being in the home during the Coronavirus is like for that family. It is absolutely a great way to reach out to that network that you have accessible to you and to seek support from those individuals, because undoubtedly, they are facing similar struggles as you might be.

WEBER: 24:39

Absolutely. And one of the huge benefits I've found of support groups is that it's the place where someone who understands what you're going through can say, "Yes. We've been through that. That happened to us last year. Here's what we tried. Give it a shot." And it's coming from someone who has actually lived it, but they can be able to share whatever tips and tricks. And of course, every person with traumatic brain injury is different and every family dynamic is different, but this is the time to get creative and try to figure out what might work. And I could think of a number of situations right now that may be more challenging than usual. So for example, people with traumatic brain injury often have health appointments that they have to be able to attend on a regular basis, be it things like physical therapy or OT. But even just checking in with their physiatrist or a psychiatry, psychologist. So what would you recommend for being able to maintain that level of health? Is that something that probably has changed as well?

KRCH: 25:52

The research are changing dramatically, even from week to week. And we're seeing that in a clinical neuropsychology community and we're seeing that in the medical community where many MDs and PhDs are moving to these online platforms to be able to serve their community of patients in the best way that they can during this pandemic. And we're seeing the shift to a lot of telerehab in instances when someone is at high risk or someone isn't comfortable going out in the community. Many doctor's offices are offering the opportunity for telerehab. So we could call head of time and ask the doctor's office if they offer those sorts of services. I also know that there are a lot of resources for mental health providers out there that are available online, individuals who provide therapy such as social workers and psychologists. They maybe previously would meet with you in person, and now there are digital



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media platforms that are enabling these therapists to conduct therapy sessions using web conferencing tools.

KRCH: 27:05

There are also some online websites that connect individuals who maybe never saw a mental health provider before, but due to the pandemic and the increased stressors that we're all facing, are starting to experience anxiety where they didn't before and maybe depression where they didn't before. And there are a lot of resources for people on the web to reach out, and you can be connected with a licensed psychologist and you can receive resources that way. So I really feel like week-to-week, they're just popping up online, do a Google search, find out what kinds of needs you have, and the opportunity to receive all kinds of medical and mental healthcare online or remotely is available now more than it has been before in the past.

WEBER: 28:01

That's definitely a strong point that I think needs to be made, that mental health is definitely something that is likely to suffer right now as people are increasingly concerned about the Coronavirus and how it's impacting day-to-day life, how it might be impacting the economy. And so being able to reach out for those resources and know that they're there. They probably look a little different than they used to before. But I know at least here in New Jersey, there is a mental health hotline. I believe it's njmentalhealthcares.org. And we can post that information, and that's kind of broad-based and open. But a lot of the organizations related to traumatic brain injury and including other disability populations are also offering more pointed services as well. So you could be potentially connected with someone who is understanding the population and the challenges, but also in this current time and what may be going on. So it sounds like maintaining one's mental health right now is really-- well, maybe a challenge, but is definitely a very important task. Dr. Krch, what do you recommend for kind of day-to-day maintenance of mental health and being able to come out of this thing kind of more emotionally strong?

KRCH: 29:40

Well, there are a few things that one can do in the day-to-day. The first thing I think of is the constant barrage of news media coverage about Coronavirus, and much of it is negative. And a lot of it is important to consume to understand what's going on, what are the latest developments, what is the CDC recommending. And that's important to view that, but I think it's important to keep in mind the amount of time we allow ourselves to be exposed to that information. I recently was watching a webinar put out by Montefiore Hospital on anxiety and Covid-19, and they made a really nice recommendation to think about consuming media coverage like a meal. At mealtime, you sit down, you enjoy some food, and then when you're finished, you kind of clean up and you move on with the other activities of your day. If you think about consuming media coverage in that manner, you sit down, you purposefully look at the media, you go to the websites that you want to see, you look at the stats, the numbers, and then you close that down. Whether you're getting that from the web, whether you're getting in from a Facebook feed, it's still important to limit that.

KRCH: 30:57

And in the time in between as we talked about earlier, making sure that we're having these moments of positive engagement with your loved one, but also filling the time in between with comedy or jokes or maybe going to some of those websites that talk



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about positive news. There is a number of those websites out there. Most of the major networks actually have a tab on their page where they only post positive news stories. So one can look to those to see all of the good that's happening, the silver lining that's happening throughout all of this. There's so many heroes that are making sure people are staying healthy, the people delivering food to us, our healthcare workers that are working in the hospitals. But there's also tremendous stories of donation. And so really exposing yourself to that, it's still exposing yourself to media, but it's really seeing the flip side of it. So that's really one, the news coverage.

KRCH: 32:02

The second thing I would think of is trying to do as many self-care activities as you can. So that may mean stretching first thing before you get up and start your day, taking a hot bath at night before bed to relax yourself, stepping out into the sun. Maybe if you have that planned schedule with your loved one and you have a timed break of 20 minutes, you go outside and just let the sunlight shine on you for a little while or play with your cat or your dog. Those are all really great ways to connect with each other and to disconnect from the technology and disconnect from the stress of the pandemic and really remember and remind ourselves what it's like to be alive and what it's like to enjoy life.

WEBER: 32:49

It sounds like you're definitely highlighting the limit the negative and enhance the positive. Just to at least make sure we have some semblance of balance in this time where it's really easy to get really over-weighted by all that's negative right now.

KRCH: 33:08

Yes.

WEBER: 33:10

So protecting one's emotional health is definitely important, but I can imagine that the cognitive health difficulties that people see after TBI time-to-time is also going to create these sorts of challenges that might need new solutions. So Dr. Chiaravalloti, how do you think that people could overcome those cognitive impairments specifically related to all these new things we're being asked to do to prevent infection by the Coronavirus in the house?

CHIARAVALLOTI: 33:40

Specifically related to cognition, we talked about one scenario earlier where the caregiver can set up a schedule to help facilitate the day and the efficient running of the day. But in regard to cognition, there are a lot of other issues that may come up particularly in regard to Coronavirus. And I'm going to use two-- I'm going to share two specific examples. So one is this emphasis on washing our hands. We have to wash our hands a lot, and a lot more than we normally do. So that's a new experience for many of us to think about washing your hands as soon as you come in the door and before you touch this and after you touch this, and whenever you think of it, go ahead and wash your hands. That's a very different way of thinking about washing our hands than what we're typically used to. So for someone who has a brain injury and they have difficulty adapting to new situations which results from executive dysfunction or may have difficulty remembering new information because of their memory problems, this is something they're going to have difficulty remembering to do.

CHIARAVALLOTI: 34:49

So one thing that may be helpful is to post signs, and sometimes it's words, sometimes it could be for someone it may be an image that you cut out of a



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newspaper or you print from the internet of someone washing their hands. So when you walk through the door, what's the first thing you see? Maybe it's another door in front of you. Maybe it's a step. Maybe it's a basket. So you hang a sign that has a picture of someone washing their hands, and that prompts the individual, "Okay. I have to go wash my hands. This is the first thing I have to do." Or when you're in the kitchen and where would you normally be setting up your meal? Where you're going to be doing that, post a sign that has someone washing their hands, and that will remind them that, "Okay. I better wash my hands now." And doing that in various-- putting a sign like that in various places around the house is going to be helpful, because they're not not washing their hands intentionally. They're simply not thinking of it. So all you're doing is prompting them to engage in this activity.

WEBER: 35:50

And I could see that even if someone with a brain injury would understand and remember on, let's say, Monday, that information may not necessarily stick throughout the rest of the week. So I can imagine it can get quite frustrating for someone to have to continue reminding their loved one of this very important thing over and over again. So I like the idea of kind of outsourcing the reminding to a sign or some other sort of propensatory strategy. This way so that it's doing that job of reminding the person, but it's also preserving the caregiver/brain-injured person relationship as much as possible and keeping it more positive rather than having one person feel like they're constantly nagging the other or that another person feels like they're constantly doing something wrong.

CHIARAVALLOTI: 36:47

Right. No one ever wants to feel like a nag. And even if the person isn't paying attention to the sign, the caregiver can simply point to the sign as they walk by. You don't have to say anything. Simply engage their attention toward that sign, and they'll go ahead and do it. So another common situation, and this happens in my house all the time, is Amazon delivers a package and there's this box sitting on the front stoop. Your initial inclination, no matter who you are, is to go grab that package and bring it in the house. But we've been taught that that package could be carrying the virus, so that is not the best action to engage in. So what you really want to think about is perhaps telling the individual who has the brain injury, "You know what? Don't take anything in. One person in the household is going to be in charge of that." And that's actually the way we've set it up in my house. There's one person that is in charge of taking everything in from the front stoop, and that person brings it over to a specific place, cleans it off, takes out the contents, cleans off the contents, and gets rid of the box itself, all either while wearing gloves or between hand washings. So it's done in a very clean environment, and everything related to that package is then disposed of, and we know that the virus did not get in the house.

CHIARAVALLOTI: 38:10

And that's an activity that I would suggest. I would suggest that the caregiver says, "I'm going to be in charge of bringing things into the house. So if you see it there, don't go and get it." And that's a very difficult thing for someone to do, particularly, someone who has executive functioning deficits. Because what you're asking them to do is inhibit a natural response. That natural response is to go out and grab that package, but you're asking them to inhibit that response. And that is going to be difficult, and it may take some time in order to get them to really be able to do that



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consistently, just walk by that package. It may even take hanging another sign, "Don't take anything inside." So that the person remembers, "Okay. I'm not supposed to take that in." So they stop and think. Because inhibition is about making someone stop and think. Don't engage in your automatic behavior. Stop and think. So even if you put a stop sign on the door, that might trigger them to think twice before they go and grab that package. So that's another thing that might help with dealing with these cognitive deficits in this current environment.

WEBER: 39:17

Right. And especially if, let's say, the household had been previously divided in terms of tasks that allowed everyone to feel like they were equally contributing. So let's say it was the brain injury survivor's usual job to go in and get the mail or get a package from the steps or check on something, bringing the garbage back and forth from the driveway. Those tasks may, at the moment, be not quite as safe because of this special circumstance. So it may actually, from what you're saying, sound like that we might need to consider rearranging household tasks based on what is going to be safer from the viral perspective versus a little bit more exposed for someone who can cognitively manage all of the tasks needed to make sure that the household is safe. So in order to still allow the person with a brain injury to feel functional and that they're supporting the household, they may just need to be reassigned to different tasks and then put in those barriers that you've mentioned in place in order to give them that reminder of, "This is something that's different now, and we can't act the way we used to in terms of our usual tasks."

KRCH: 40:41

And while Dr. Chiaravalloti was talking about some really great examples for prevention, the stats suggest that many of us might, unfortunately, be faced with getting the virus ourselves. So one of the things that would be really helpful for caregivers who probably have already been down the road of having unexpected situations happen, they probably already have a network of go-to people, people they can contact in the situation where an emergency crops up. But they might want to think about what are alternative resources that might be available to them. They might want to think about a contingency plan. So in the event that you as a caregiver or your loved one with traumatic brain injury get the virus, what sort of scenario would you be facing with? Similar to the way a family who has small children might plan what happens in the event of a fire. Where are the fire escapes? How do we exit the house? Where do we meet? A caregiver might want a plan for that contingency. What happens in the event of the Coronavirus hitting our home? How would we deal with it? Would we be able to utilize one bedroom as the quarantine room? How will we get food into the house? How will we make sure that the prescriptions are still being picked up and delivered to us?

KRCH: 42:12

And although we hope that we don't have to face that eventuality, planning ahead and thinking about what those steps might be will potentially take a lot of the stress out of how to go about doing those things should the moment actually arrive. Because you've given it some thought, you've figured out what the steps you need to take are, you maybe already had a list of names and numbers of people you can reach out to to help make sure that meals get to the house, prescriptions get to the house,



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and then you can better manage dealing with the virus when it does come to your home.

WEBER: 42:49

I think that's a very important point, and one that, of course, we don't like to think about what might happen in those sorts of dire situations. But it's definitely good to plan ahead. Not to say that anyone is at their usual comes levels of stress right now. Everyone's stress is probably a bit heightened, but it's probably significantly less stressful to go through that scenario right now rather than waiting until perhaps something starts to develop and having to start to think about it in that moment. So I like that idea of being as prepared as possible. And going back to what you had been saying earlier, there are some scenarios where people who are caregivers of loved ones with TBI, that they may be better adept at having to manage these different challenges that we're facing now with Coronavirus, because they've had to plan in advance for a lot of things that many other people just take for granted. So this is definitely a skill set that caregivers can rely upon that they often are the ones charged with having to think five steps ahead to figure out how to get to the grocery store and them, to their loved one or how to complete other sorts of daily activities. So this is something that they're probably especially skilled at and can be very useful for. So in this case, probably an ounce of prevention is worth a pound of cure. And in terms of managing the stress, if and when the Coronavirus does hit in a given household. So I think that's a really important point to make.

KRCH: 44:39

That's an excellent point, Dr. Weber. As I've seen in the research that I've conducted over the years with caregivers, they are an extremely resilient group of individuals, and the Coronavirus that we're faced with right now is a challenge for all of us. But the resilience that the caregivers exhibit, I have no doubt that they'll pull upon those resources to help us in the current pandemic and get through it.

WEBER: 45:07

Well, I want to take a minute to thank Doctors Krch and Chiaravalloti for your expertise, and I know that they'd join me in saying that we really are amazed by the day-to-day that people who are caregivers of those with TBIs have what they exhibit. And we really support you with this endeavor. We'll be posting some program note that have some of the resources that we mentioned in the podcast, so feel free to follow those. And additionally, to give a quick shout-out to Dr. Krch. She's currently operating a research study for caregivers of people with TBI that is entirely virtual, so it's as Coronavirus-friendly as possible. So for more information on that, you can find how to see if you're eligible on the kesslerfoundation.org website. And check out our playlist on SoundCloud. We'll be doing some more of this series as we face these unprecedented times. But thank you very much for listening, and stay well. [music]

ANNOUNCER: 46:14

Tuned into our podcast lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. In new 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 at Kessler Foundation. Check back soon to listen to more Covid-19 podcasts on our playlist. The link is in the program notes. Listen on iTunes, Sound Cloud, Spotify, or wherever you get your podcasts. This podcast was recorded on Wednesday, April 8th, 2020 remotely and was edited and produced by Joan Banks-Smith, creative producer for Kessler Foundation.



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