

## The Lewin Group

### Supporting Family Caregivers of Older Adults through Times of Stress and Isolation

April 30, 2020 - 12:30pm EDT

**Alana Nur:** Thank you and welcome everyone to the webinar Supporting Family Caregivers of Older Adults Through Times of Stress and Isolation. My name is Alana Nur, and I'm with the Lewin Group.

Today's session will include a 60-minute presenter-led discussion followed up with 30 minutes for a discussion among the presenters and participants. This session will be recorded. A video replay and a copy of today's slides will be available [resourcesforintegratedcare.com](http://resourcesforintegratedcare.com). The audio portion of the presentation will automatically stream through your computer. Phone lines for this presentation are also available. To access that number, click the black Phone icon at the bottom of your screen.

This webinar is supported through the Medicare & Medicaid Coordination Office at the Centers for Medicare and Medicaid Services. MMCO is helping beneficiaries dually eligible for Medicare and Medicaid have access to seamless high-quality health care that includes the full range of covered services in both programs. To learn more about current efforts and resources, please visit our website or follow us on Twitter for more details. Our Twitter handle is @integrate\_care.

At this time, I'd like to introduce our moderator, Carol Regan is a senior advisor to Community Catalysts Center for Consumer Engagement and Health Innovation and has over 30 years of experience with national and state-based public policy and advocacy organization. Carol?

**Carol Regan:** Thanks, Alana, and welcome everyone. I'm pleased to be joining you all today from Community Catalyst, a nonprofit, consumer health advocacy organization whose mission is to ensure that all consumers and communities can influence local, state and national decisions that impact their health. We're particularly focused on the needs of vulnerable populations, including older adults. We're proud to have been partnering with the Lewin Group and MMCO and the American Geriatrics Society for many years on educational efforts such as these webinars to improve care for consumers who are dually eligible, duly enrolled in Medicare and Medicaid.

I'm so pleased to introduce our faculty for this webinar who bring a depth of expertise, years of experience and strong commitment to supporting family caregivers. So let me first introduce Kathy Kelly. Kathy, as the Family Caregiver Alliance executive director, Kathy oversees programs at the Bay Area Caregiver Resource Center. That's in California, providing direct services to families in the San Francisco Bay Area, California Policy Collaborations and the National Center on Caregiving. During her tenure, the organization has grown from a grassroots program to a national organization that provides leadership on supporting family caregivers with best practice interventions,

public policy, state system development and leading edge research. Kathy represents the agency on a variety of national coalitions that work toward coordinated care that includes family caregivers as part of the care team. Kathy recently was the co-chair of the San Francisco Strategy for Excellence in Dementia Care expert panel. She has written and lectured about caregiving, public policy, program and system development and the use of consumer technology.

Then we'll have Dr. Erin E. Emery-Tiburcio. Dr. Tiburcio is an associate professor of geriatric and rehabilitation psychology, and geriatric medicine at Rush University Medical Center in Chicago. She's a fellow of the Gerontological Society of America, past president of the Society of Clinical Geropsychology, and past chair of the American Psychological Association's Committee on Aging.

Currently, Dr. Emery-Tiburcio co-directs the Rush Center for Excellence on Aging and CATCH-ON, which is a health Health Resources Services Administration-funded Geriatrics Workforce Enhancement Program at Rush University Medical Center in Chicago.

And then we're pleased to have Bryan Godfrey. Bryan completed an undergraduate coursework at Indiana University in Pennsylvania and a Master of Art in Publishing and Writing from Emerson College. After graduation, Bryan taught English and also courses on cultural diversity. Fascinated by human difference and incensed by inequality, Bryan moved to Philadelphia where he obtained a second master's degree in social work from the University of Pennsylvania. He became a licensed clinical social worker and spent the next four years providing outpatient psychotherapy for underserved adults in North Philadelphia. Ultimately, Bryan moved to North Carolina for his current position at the University of North Carolina Geriatric Specialty Clinic, where he serves patients and their caregivers as the clinic's only social worker.

If you can see we have an incredible faculty. So we're so pleased that they have joined us today. And let's go to the next slide.

So just wanted to recap these learning objectives around, hopefully, at the end of this you'll understand more and be able to describe some of the challenges facing caregivers of older adults, particularly during this current COVID public health emergency, identify strategies for assessing and addressing caregivers' emotional health and the supports they need during times of stress and isolation, many who are taking on new responsibilities. And lastly, to describe really practical tips for effectively linking caregivers to the support services provided by healthcare and community-based organizations. Next slide.

So, this is what we're going to go through today. I'll briefly describe, we're going to do a few polls so you can get a better sense of who's on this call. Kathy is going to talk about supporting family and friend caregivers. Dr. Tiburcio will talk about caregiver mental and emotional health. Bryan will talk about caregiver assessment and resources. Now we're going to open it up and have a panel discussion. And then open it up again to you all for audience Q&As. And at the end of this slide deck, you will see and be offered a list of resources for you as you're continuing to do this work after this webinar. Next slide.

So we like to get a better understanding as the faculty address some of your questions, what best describes your professional area. And again, you may overlap in here, but just add what you think best describes the role you are in today.

Okay, a couple more seconds. Your vote in? Good. And now can we see the results of the poll?

Terrific. Okay, so we see a number of people, case managers or care coordinators or health plans, almost half; a number of other people who work for health plans; 5% providers and some people in pharmacy, oh, and a number, excuse me, about almost 40% in social work. Terrific. Great.

Next polling question? So, again, they may overlap but what is the primary setting in which you work; health plans, ambulatory care setting and see the number of options here? But just choose one so we get a sense where you're working on those days. A couple more seconds. Good. And now can we see the results of the poll?

All right, so a little over half as we thought, right, in the health plan. Oh, almost a quarter in community-based organizations, some in academia and then, good, some in other kind of homecare, long-term care, ambulatory care settings. Terrific. Great. Thanks. And so the next slide?

And now I'm really pleased to turn it over to Kathy Kelly. Kathy?

**Kathy Kelly:** Thank you. Can you advance the slide please?

So I'm really thrilled to be here today, and thank you to the sponsors and the many, many individuals that work behind the scenes to make this webinar possible today. I'm going to be talking a bit about setting the context providing the framework of information. It probably is familiar to you, but I think it's good to go back and sort of put it all in a framework that we understand as we move along what we're talking about in terms of family caregivers, and some of the characteristics of older adults and families who care for them. This is the context that we understand the daily activities that may be particularly challenging, and particularly challenging because we have the pandemic, the COVID pandemic.

So we know that over 34 million individuals are providing unpaid assistance to an older adult that is over age 50. And most, if not all of these individuals, are typically in the Medicare- and Medicaid-eligible range, not all but a good percentage of them. About 60% are women who are taken care of, 40% are men. There's 14% friends and families and other non-relatives of the care recipient that are also providing some level of assistance. Next slide, please?

The complexity of care, I think is, I wanted to draw this out particularly because families are dealing or are doing many, many tasks that are allotted across professional categories. And they may be providing direct care assistance. They're talking with healthcare professionals. They're handling legal and financial affairs. They're doing housekeeping tasks, socialization tasks, all of which are the work of many, many individual

professionals, but all kind of balled up into one. But what's more important is to understand that they may be dealing with complex caregiving tasks, including medical tasks that can have negative emotional and mental and physical health effects on caregivers.

About 50% was found to have performed complex medical nursing tasks on top of ADLs and IADLs, which is administering medical -- multiple medications, changing dressings, handling medical equipment, supplying metrics on a daily basis, health metrics to healthcare professionals and so on. So these complex tasks have a different kind of impact and for a large number of caregivers their presence.

But it's not all negative. Caregivers also report positive experience, including giving back to a loved one, the feeling of closeness in providing care, reciprocity issues, honoring the wishes and plans of the older adults for their quality of life. And then also that there's many support services, education and respite that can provide the skills and tools to help families and help mitigate some of the potential negative effects of caregiving. Next slide please?

On the impact of caregiving on mental and emotional health, we know that caregivers have higher levels of stress than non-caregivers and persons that are caring for individuals, adults with cognitive impairments, particularly dementia. It could be stroke or Parkinson's, and so on. Those that have cognitive effects are particularly at risk.

We talk a lot and there's been a lot of discussion recently about social isolation. We hope there's going to be more information emerging from our experiences during this pandemic and more study into this area in particular on caregivers but we know that caregivers who have complex care needs that are performing more of these kinds of tasks in the home and have fewer social supports, and are less satisfied with their social supports, they're at a higher risk of strain, depression, sleep disturbance and poor health. So we know that all of these issues do interrelate to one another and result in a higher level of stress for the caregiver in isolation.

Caregivers report that they have higher levels of depressive symptoms and anxiety than non-caregivers and somewhere between 40% and 70% of caregivers have clinically significant symptoms of depression. And again, caregivers of individuals with dementia or other cognitive impairments have higher levels of depression and emotional distress. Next slide, please?

Now, we're going to talk a little bit about caregiving in the context of COVID. So in addition to the usual and customary kinds of caregiving responsibilities, we now add this sort of extra layer of the situation onto the caregiver and understanding that, first and foremost, we all have to learn, every one of us had to learn about extra measures for cleaning and disinfecting, washing hands and wiping down hard surfaces and so on, and also personal protective care. So we need to learn a new set of skills and a new set of protocols to put in place for our own individual lives. But in particular, this is stressful for those that are caring for older adults that are more at risk for COVID. So there's an emotional component that goes into that extra layer.

There may be financial difficulties, disruption in in-home support services. Routine doctor's appointments may be held by phone or by telehealth means. Respite care may not be available and so on. So there's lots of disruption as a result of that to our daily patterns plus understanding all of the COVID protocols as well.

Caregivers that are -- have relatives in any kind of extended care facilities are reporting a lot of distress out of not being able to see their relatives in assisted living or any other kind of extended facility. And those families may have moved in over older relatives into their home during this time, and they're taking on new caregiving responsibilities. So we're seeing all sorts of issues kind of emerge during this pandemic, either having new people into the home or not being able to see your relatives on a routine basis. Next slide, please?

Some of the other considerations that we know that caregivers need additional supports and services during this time, and that we needed to pivot really, really quickly to make sure that we were able to provide these in an online basis using visual platforms like Zoom and other webinar kinds of platforms so we're able to deliver our education programs. But we also knew that we needed to use telephones for some of our families who are not able to access the internet at this time.

So the services and supports, wellness check-in calls to make sure that people are doing okay, making sure that we have information going out about the protocols, education and supplies where they can get those supplies. Or, related to COVID-19, there may be other issues around dementia behavior because normal routines may be upset. So strategies for that. Stress reduction strategies. There may be bridge needs for food, consumable supplies, transportation. There's a lot of flexibility in contracts for services now to be able to provide vouchers or gift cards for food and other types of needs for the family. Short-term counseling for people who need better coping skills, direct skills training, strategies for adapting to new situations and guidance around care and changes in care. Next slide, please?

So when connecting family and friends during this time, it's really important to reach out to the local services that are in your area, the Area Agency on Aging, Aging and Disability Resource Centers, 211 or 311. They're called different things at different parts of the country. These are all local resource clearing houses that you should be in contact with to understand what are the changed conditions for the community, for services that are normally and customarily offered and may have been modified or closed during this time. If you haven't started a resource sharing roundtable, it's really a good idea; it's where you get all the informal information that you need to be able to make your recommendations for services that are still available in the community. And gather lists of resources for caregivers and disseminate widely.

Included in this presentation, we put together resources that we thought would be the most helpful to you. So we encourage you to go ahead and disseminate those as widely as possible. Many of us have curated the large amount of information that's coming out this time to really hone it down to be important or meaningful for caregivers. Convert all your support groups to a way in which people can participate online or on the telephone and

seek other ways, as I mentioned before, how you do your educational programming. Next slide, please?

These are some of the selected resources that we have found to be helpful. Again, we have curated this firehose of information coming out of where we sort of refined down to COVID resources. I also wanted to make mention that for those of us who are dealing with more difficult kinds of tasks, direct care tasks in the home, there is -- many of these resources in here relate to those videos that you may be able to show to families. There's a series of medical task videos which is quite robust from the Home Alone Alliance under AARP, again, under CAPC, UCI Health and the CATCH-ON a program. All of these are short videos of three- to seven-minute duration on very specific tasks so you can take them out and use them as you find tasks that are appropriate to the situation. So it's a great training vehicle that is a quick turnaround time that you can really help along with the tasks and tip sheets that are contained in here. You can really help families with maybe some of those more difficult tasks that they're dealing with at this time.

So I've reached my end, but I'd like to turn it over to Erin now.

**Erin Emery-Tiburcio:** Thank you, Kathy, very much. I'd like to echo Kathy's gratitude to the organizers and supporters of this webinar. It really takes a village to put this together. Next slide, please?

So Kathy talked about the multiple tasks of caregiving, the responsibilities for medical and cognitive issues as well as behavioral issues. And not only make caregivers be dealing with these issues of their care recipients, but caregivers themselves, given that many of them are older adults themselves are also dealing with their own medical illness, their own potential cognitive decline, their own anxiety and depression. And then when we put that in the context of potential economic security, and multiple social stressors, so we also have a number of caregivers who are in what we call the sandwich generation or taking care of children and taking care of their older-adult parents. So a wide variety of different kinds of stressors that make the complexity of caregiving potentially incredibly overwhelming. Next slide, please?

So as we think about the sources of stress, not only are we talking about sort of that medical complexity, but interpersonally, that lack of control and predictability. So with a disease progression, whether it is something like Parkinson's disease or Alzheimer's disease, there may be unusual or unpredictable behaviors, mood swings, wandering, paranoia, and particularly when routines are upset, it can feel like there's just no control and no predictability. So that can be incredibly stressful. Even on a good day for an individual with some of these progressive diseases, it might be incredibly challenging to manage behaviors that one can't predict.

And also as part of the role of caregiver, many folks lose support. So if they were out in the working world and had given up their job perhaps to become a caregiver, and/or are spending a fair amount of time in that caregiving role, there isn't time often to connect with social supports that may have been in place prior to taking on that caregiving role.

And because many do give up things like jobs and income, that economic insecurity can be a significant stressor.

So as the disease and aging progress, new symptoms might emerge. So it's possible someone is taking care of an individual with cancer. And that -- as aging continues, and as the disease continues, as new symptoms emerge, there's an idea that things are getting worse over time. And with that feeling of, I don't know what I can do to manage this next obstacle as it comes, there can be these intense feelings of helplessness -- I don't know what to do. I don't have the resources to manage all of these things that are coming up. Next slide, please?

So particularly during COVID, all of these things may be exacerbated. So the elements that I just discussed are caregiving in normal times. Now, the lack of control and predictability, with virus spread, with communities closed, with questions all of us are experiencing, this level of uncertainty in our environment, and whether it's safe to go out into the community, whether it's safe to take their care recipient to an in-person health appointment, particularly right now, as health systems are beginning to open back up in certain regions of the country, what does that mean? And how do I manage all of that?

This loss of social support is particularly intense right now, with social isolation just due to physical distancing and to shelter in place. I would emphasize here that it would be helpful to talk about physical distancing rather than social distancing. It's really unfortunate that our -- the nomenclature around this has talked about social distancing, because that gives the impression that we should be distancing socially, when in fact, we should be distancing physically and connecting socially. But that's a strain for caregivers who may not have even normal supports where folks might be coming into the home where home health aides may be coming into the home, but perhaps they're afraid that that might not be a good idea right now. Who knows what might happen if a home health aide might come in? So there's a lot of fear around that, for a lot of older adults and for caregivers.

And the perception of things getting worse. Any of us who read the newspaper, there's a lot of doom and gloom, and there's a lot of doom and gloom about what's going to happen to the virus. Might there be another surge? What's happening to our economy? Will we ever recover. And so, caregivers who may be struggling with joblessness now may have even larger fears about what this is going to mean as we move through the time of the pandemic.

And further, feelings of not having what it takes to meet the next obstacle. My goodness, that helplessness is overwhelming. And what happens if the caregiver gets sick and can't provide care? Or, if I don't have correct PPE or if my home health provider who comes to the home doesn't have PPE, now what? If I don't have what I need to manage these stressors, I may become incredibly overwhelmed. Next slide, please?

So as we think about this social isolation, caregiving in and of itself doesn't really allow for a lot of personal space. So very often caregivers are sharing a home with their care recipient, and so don't have a private space. And as we are all encouraged to stay inside

the home, there isn't really much of a break from that. And as work in community roles decrease outside the home, there is that added social life disruption. And of course, the shelter in place. So that loneliness, even during regular times among caregivers, is associated with powerlessness, helplessness, full responsibility, and leading to depression. And that's outside of COVID. And as Kathy mentioned, we're starting to do more research and understand the impact of COVID and how we get a sense of what this means now. My guess is that it will be that much more exacerbated during COVID. Next slide, please?

So as caregivers' lives are changing when they become caregivers -- for some becoming a caregiver is a welcome role change and some might experience that as an opportunity to care for a loved one, which is wonderful. Some might also experience grief as they give up aspects of their lives to become caregivers. I mentioned the idea of giving up jobs, they may be giving up finances, and giving up hobbies.

And during the COVID pandemic even more individuals are taking on caregiving roles, and people that are already in caregiving roles might be taking on additional responsibilities. So this may bring up additional feelings including grief. And given the number of people who are dying with COVID, some may even lose the person that they're caring for during COVID. And because we're not able to attend funerals in the way that we normally would, that sense of closure may not -- people may not have that opportunity for a sense of closure. Next slide, please?

So as we think about then, what do we do with this? Well, assessing caregiver mental health is critical in this time, and whether you're working for a health plan, whether you're a social worker in the community, utilizing freely available anxiety tools and depression tools, so there may be a lot of what ifs in managing anxiety; what if my loved one gets sick, what if I get sick, what if, what if?

Anxiety tends to live in the future, and thinking about what might happen in the future. So that experience then might be things like worry, tightness of the chest, shortness of breath, cold hands and feet, which, if we're not careful, can send folks to the emergency room. And so being able to assess that and provide resources in the home, is critical.

Depression tends to live in the past; what I would have, could have, or should have done, and so people who are experiencing symptoms of depression, may be kind of stuck in the past and may experience sad or flat mood, lost of interest, change in appetite, excess guilt, low energy, poor concentration, all of that leads to an inability to being an effective caregiver.

One could use the patient health questionnaire 9, which is free online, I believe we have these resources attached as well.

Additionally, grief, asking about losses, asking what kinds of losses the caregiver may have been experiencing, asking about social connection, job, and death. And so for all of the folks who are with me to this webinar, please do assess, and please do provide referrals. Next slide, please.

Some interventions that you may be able to offer during the time, just being at home, creating as much routine as possible, humans are creatures of habit, and the degree to which we can maintain a routine is actually really helpful for almost all of us, getting physical activity, healthy food, sleep, limiting alcohol, all of those kind of routine things that we can reinforce in the home, connecting to others as much as possible, friends and family, Kathy mentioned video platforms to the degree possible, support groups, there are some wonderful opportunities online, there's some fantastic skill building tools offered by family caregiver alliance, Kathy provided a lot of those tools.

And referring for psychotherapy; this is an unprecedented time where telehealth is available, CMS is reimbursing for video visits and for telephone visits. As a psychologist who provides services to older adults and to individuals through primary care and to caregivers, I've been doing quite a few telehealth visits and they are incredibly helpful. It's been wonderful to see some of my patients in their homes, and to meet some of their family members in the home, so it's a wonderful opportunity to be able to provide those services and I am very hopeful that these services will continue to be reimbursed as we move forward, particularly for caregivers who are homebound, the need continues.

So in the next slide, one example that you may be able to share with caregivers. Russ Harris created FACE COVID as a mnemonic for us, FACE, focus on what is in your control. Caregivers often have so many things they can't control as do the rest of us, identify what's in your control, and that one thing is our own behavior, we can control our own behavior, our own choices, focus on that, acknowledging your thoughts and feelings. If we just deny them, they're likely to come out in ways that we least expect and least want them to.

And for caregivers, that may mean not providing the level of care that they would want to, so acknowledging those thoughts and feelings. Coming back into your body, taking a deep breath, back into the present moment, again, that anxiety that takes us forward and the depression that takes us back, come back into the present moment, right here, right now. Take a breath, and engage in the task at hand, right in front of you, engage in what you're doing.

For people who want to learn more about this, Russ Harris has created a fantastic 5-minute video, and there's a link in the slides, that talk about committed action and opening up, identifying your own values, the resources you have, and of course, in COVID, disinfecting and physical distancing, not social distancing.

So FACE COVID with focusing on your own control, and with that, I'll hand it off to Bryan. Thank you.

**Bryan Godfrey:** Thanks, so much, Erin, I love that FACE COVID acronym and the wonderful messages of mental health that you've given. Thank you. Thank you all for being here, so much, it's a pleasure to be surrounded by other case managers and social workers. Next slide, please.

Alright, I just want to look at a case study with you all today, it's what we often do within social work. Talking today about a woman named Mrs. B, a generally healthy 72-year old, living in the suburbs of North Carolina. Prior to COVID-19, she attended a day program, every day, and loved the chance to get out of the house and socialize. She was specially enjoying getting away from her husband, Bob, who she found to be argumentative, and a gentleman who preferred to remain at home anyway.

Now that her day program is closed, though, Mrs. B is stuck at home and she's clearly unhappy. Her daughter, Patricia is a 53-year old mother of 2, her kids are aged 14 and 19 and Patricia lives about 20 minutes away.

She works as a home care certified nursing assistant, or CNA, and Patricia has noticed that her mother is feeling down and often hears a conflict -- but she worries about getting involved in her parents' business, and possibly exposing them to COVID. She's also worried about her own kids, who are home during the day since school has closed, and you know, kind of wonder, if a 19-year old can really be that good of a babysitter for a 14-year old.

One day, Mrs., B and Bob had a big fight, and when Patricia gets home, she finds her mother on the sofa in her house, with the kids trying to comfort her, Patricia calms her mother down and things go back to normal, but she starts having trouble sleeping and she's worried about the next big fight, and about COVID-19 in general. Next slide, please.

I'm sure that will sound familiar. Pieces of that will sound familiar to many of you, so in this slide, I wanted to take a little bit of a look to see what are some of the needs that we can identify in a scenario like this one? And I think there is quite a few.

So from Mrs. B, we can notice that she seems, to me, something to do during the day, to replace her previous activity, and some time away from her husband probably wouldn't hurt, but of course, that's very challenging right now. Sounds like she might need some mental health support as well, and probably everybody can use COVID-19 education.

As for Patricia, it sounds like she's having -- she needs to reduce her stress, she needs to improve her sleep. Some ongoing caregiver support, would be really helpful, maybe some mental health support, and again, the COVID education.

As for Bob, sounds like he could use some time away from his wife, and he may even need some healthcare, mental health support might be important for him as well, and he too, might need something to do during the day, with that COVID-19 support. And finally, the kids may need some childcare support, some activities to do during the day, some mental health support themselves, possibly, and again, that COVID-19 education. Next slide, please.

Alright, talking about addressing these needs, so I think it can be helpful to start with priorities. And we need to remember we can't do everything, and some things just can't be addressed right now. So we're paying attention to what issues can wait, what needs to be addressed immediately, and what might not need to be addressed at all.

We also want to think realistically about what might change and when we should look at these problems and decisions again, if we can't tackle them right now. We also need to be aware of resources. Our other two presenters have mentioned this a bit, it's fantastic. We need to know what resources are available in the community, including financial, social, and other resources. We need to know what strengths does each person in this situation possess, how might they be able to help and how might they want to help?

And in particular, one of the most powerful things we can look at is, what has worked in the past, it's important to remember that people are not in existence in isolation. They've accomplished other things before, so we can look back at previous successes.

Finally, looking at values, motivation and goals. What does each person actually want? What are the parties interested in, or willing to try, and are there any requirements of your agency or of the law that need to be followed here? Okay, next slide, please.

Looking at how to address some of these needs, now there's a lot of information that we could possibly cover here, lots of things we could do to intervene, but let's just touch on a few of these possibilities.

So for Mrs. B, it sounds like someday activity is really important for her, and she's having a hard time now that she can't go to her day program.

So one thing to consider of course, is virtual meetings, we found a lot of spaces being opened up virtually in terms of Zoom, or other online meeting platforms, and a lot of day programs have actually shifted to having some programming online. Another option is local senior centers, who also are doing some programming online, and there's also caregiver support groups that tend to be doing some video and even audio conferences as well. So depending in the role, that might be something to consider.

This also might be a good time to look at exploring a new hobby, truly this is something that creates some space between people who could use it right now, and there's a ton of information available on places like YouTube where you can try some exercise or try a new hobby, something that might be interesting to attempt now that we have the opportunity to do so.

And I think exercise should really be emphasized here, not only is it good for our bodies, it's actually fantastic for our minds. And some have said that if exercise was a pill, it would be a miracle pill, and the most powerful mental health medication that we've ever achieved, you know. So exercise cannot be understated.

We mentioned the time away from her husband, whether it's just to take a short walk outside, sit on the porch or even just to go to a different room, anything can be helpful, and mental health support can't be underrated either. You know, sometimes, we have the perception that older adults are not open to this. I found that that's true sometimes, and probably in equal amount of time, it's not true.

So we really want to explore this possibility and to know that all people under stress can use mental health support.

Going for Patricia, of course, the same mental health support could apply here. In terms of reducing her stress and improving sleep, there's a lot of things to consider. Cognitive behavioral therapy has been a gold standard for both of these, so that obviously can be pursued in a formal capacity through talk therapy. But we could also look at something like mindfulness through some free apps and websites, and we'll have some resources here in just a bit for you.

Lots of caregiver support is needed regardless of COVID, and especially when it's active, so whether it's a Facebook group, a video group, a phone-based chat, whatever might be appropriate, the supports are out there if people can be made aware of them, but at least, they have the chance to engage with them, if they choose.

Looking at Bob's situation, some time away from his wife might be helpful for him as well. I can actually draw from my own experience with my dad here, once he discovered it, he never turned back. There were so many amazing shows that he never considered. That and also doing Sudoku puzzles, turned out he absolutely loves them. So whether it's a new hobby or something new to check out like that, there actually might be a way to explore something new here.

And of course, with homecare, we might need to think about some pros and cons of actually bringing someone into the home, and maybe even consulting with the doctor to see if it's worth it, to give the caregiver some break and get some medical attention, even though there's an increase in the COVID risk. Finally, looking at kids and their child support, the child care support, there's a lot of local supports that are out there, but they can be difficult to find a lot of them have shifted in capacity.

So whether it's contacting the Department of Human Services, or perhaps, Patricia's employer, there could be powerful resources here for child care in the community.

And finally, something to do during the day for the kids, could be really helpful as well, of course, whether it's a virtual exercise program on YouTube, some kind of new games that they can play or a way to keep them engaged and just out of trouble, it can be difficult to brain storm, but again, looking to the past can be successful here.

So just briefly, next slide please, I wanted to show you some resources that are available for you and what to ask about. Won't go through the whole slide, but I just want you to know you'll have access to this list. On the left hand side, you can see some groups to consider contacting, and on the right hand side, you can see what's out or of course, if you're assisting someone, you can advise that they do so.

I think it's important to let people know that they can reach out by phone to learn what's available, and to not assume that something is off the table, just because of COVID. Also, giving them that second column on the right there, something to ask about, can be helpful. So when they're calling, they're not calling blind, they're actually asking for something in particular.

Next slide please. Okay, and then finally, as promised, here are a bunch of resources, I'll let you come back to these another time. We've specifically put together some for

physical activity, for mental health, and some hotlines just in case any of that is useful, and these are all things that can be accessed from home without risk of COVID exposure.

**Carol Regan:** Great. Thank you all so much. Can you hear me? Okay? This is Carol, I'm back to thank all the panelist for great -- lots of information, lots to digest and so many really practical tips and resources moving forward, so thank you all.

Now, we're going to have a brief panel discussion, before we open up to Q&A with you all, and I'm excited about following up on some of the things that you all asked as registrants -- questions when you registered, so we want to tap into some of those.

So first, let me ask Kathy, how can providers, a number of providers on the phone, lot of care managers and case managers, how can they support individuals who are new to the caregiving role, they're taking on new responsibilities. Do you have some suggestions on that, follow up on what you've all talked about?

**Kathy Kelly:** Yes, I think it's important to be able to assess you know, what's really going on with families, because we're new to the role, we don't really know what their capabilities are at the present and what might be problematic for them currently, and how they can address this in the future.

There's a variety of different assessment tools -- we referenced a number of them throughout this presentation -- that will get at asking the questions around direct care, the direct care situation and we'll be able to guide the conversations that you have with families. It's always great to use a tool whether or not you're actually filling it out or using it to guide a conversation. It's important to be able to ask the questions that are going to yield the information that you need.

And particularly around understanding the caregiver situation and challenges, and relating it to some of the tasks that they may be taking on, especially if they're new. They can be behavior or direct care staff. There are a number of you know, assessment measures that will ask these questions in a way that will enable you to understand better, for example, we use the Teri -- troublesome behavior checklist question, because it asks the question around you know, what are problematic behaviors, but more importantly, does this behavior bother you?

Not every behavior that might be problematic to one, is problematic to another family member for example.

So it guides the conversation so you know exactly how -- what kinds of resources to bring to the table for that individual.

So it's really important to look at the direct care situation, what kinds of issues are they dealing with, will be dealing with for planning, for care, taking on particularly if they're new to the role, it's particularly important for them to understand the relationship and communication with health care professionals in the systems around their care.

So there's a number of relative resources that we've provided, I think, that can then guide you in these kinds of conversations.

**Carol Regan:** That's really helpful, Kathy and I think you've talked about this, all of you talked about the resources, and there are so many could benefit from it. Bryan, do you want to briefly add anything to that? Because you also have talked about resources and supports and how you know, every person is different. Anything you want to add to that?

**Bryan Godfrey:** Yeah, definitely, thank you. When it comes to resources, I think one thing to always remember whether you're dealing with a new or an experienced caregiver, is that folks are often pretty overwhelmed as things already are, and sometimes, giving them a large sheet of resources can just be too overwhelming to follow up on.

So one thing you can do is actually really get to know that caregiver's position, just as Kathy was talking about. Choose a couple of high-priority resources that would be really helpful for them to engage with potentially, and then provide whatever detailed information you can, to help them connect.

So I'm talking about not only giving a generic resource, but actually, if possible, a person's name and phone number where it feels like a move vetted or more personal touch. That way, you're addressing a specific need in a way that feels much more helpful and personalized, and for the family.

You know what I would just say in general, when you're dealing with new caregiver, remember that they may come from a place of really loving and cherishing their new role, they may be resentful, they may be anything in between. So we need to understand that it may take time for them to just wrap their head around this new role, let alone actually do it well. So this is all a process for all of us.

**Carol Regan:** That's a really helpful point. And speaking of that, sort of right into one of the next questions I wanted to ask you and I would actually direct this to you, Erin, so what recommendations might have for providers who support caregivers who are feeling -- I mean you talked a lot about this -- but just to (technical difficulty) sort of again, those who are feeling isolated, that don't have the same supports, what would you recommend for those caregivers?

**Erin Emery-Tiburcio:** Absolutely. I think the first thing would be to echo what Bryan and Kathy identified in terms of assessing the type of isolation that caregiver is experiencing, it may be specific to the caregiver role or it might be a broader feeling of isolation. And so understanding exactly what the concern is rather than making assumptions about it and then so many opportunities to connect; the support groups that are online. So for example, those living in the Chicago area, Rush is offering a support group right now for caregivers and my guess is that there are many that are local and you can identify what opportunities there are. And just to echo the telephone video platforms. And making referrals for telehealth. So psychotherapy can be a fantastic resource in this time as well.

**Carol Regan:** Great. Yeah. And Kathy, just to -- I mean, I hope you can add to that. I'm sure you can add to that about just other things that you might -- recommendations, really sort of practical tips on things that can do for people who are isolated. You want to add onto what Erin shared?

**Kathy Kelly:** Sure. We've talked a little bit about wellness checks. And I know that there -- this -- where you have a national call and there's been sort of a rolling shelter in place that has gone on across the country, not everyone has shut down at the same time and had shelter in place orders.

We had shelter in place orders at the beginning of March, basically. And what we found over time is that when we made calls -- during those first few weeks, everyone was just getting adjusted to their new situation and so everything seemed to be okay, they were coping as best as they can. Go back and make wellness calls now. Because as the situation elongates and there still this uncertainty, there's going to be different issues that come up. So while you may have made a wellness call in the first few weeks, as the time elapses you're going to find different issues come up for families. So it's important to go back and refresh those wellness calls, definitely. Again all of the support group information and online, I want to emphasize it as well and to make sure that you gather these resources that you have them at hand immediately to be able to provide to families.

**Carol Regan:** That's really helpful and I just reiterate this just like the one call isn't enough that is sort of frequently checking in because things change is really an important point to take away. I'm sorry but there's a fire truck in my background.

Let me just -- one more question, can we go to the next question? This particularly -- and again I'll sort of direct this to you first, Kathy. How can supervisors -- we have a number of care managers and other supervisors who help staff that they're working within a plan or a health care facility, how can supervisors or managers who support caregivers during this time of stress, how can they help those staff? What can they do?

**Kathy Kelly:** Well, first we have to recognize that we're all in this together. So all of the staff -- my staff, as social workers and all of yours are also dealing with their own issues in their own home and so we do have to recognize and acknowledge that. In some ways we need to take our own feedback that we're -- feedback our own advice to families to make sure that staff are getting -- eating well and exercising, relaxation, they're planning some pleasurable events during their days.

I think it's really important to have more frequent maybe of less duration meetings. We started to do all-staff meetings once a week just to check in because there was so much information to share, but also the situations change, they're very fluid that people need different things at different times. And to be able to bring people together and really talk about what's going on has allowed us to gather the information so we can pivot either with getting the information or the flexibility in service delivery on point so we have that constant information. But the more important thing is we wanted to bring people together. And we do this on Fridays, which is the end of the week and people are pretty

ragged because we want to know what's going on with the staff, we want to support the staff as well.

And I can't emphasize this enough that we need to have some humor and some good things to share with people during this time, too. We're -- we hear the stories, we read the newspapers as we -- the news which is not good, so we do need to have some lightness that's involved in these meetings as well. And to be able to bring together people more frequently around case issues, because when you're in an office you can go over when you have a really troublesome call or a challenge situation, you can consult a colleague. But in this case, that might not be as easy to do, so you have to plan those kinds of events to be able to bring the staff together to talk about the case issues that they're facing as well.

So we all need to be kind to one another but we especially need to take care of our staff at this time too, because they're dealing with all of their issues at home and also shouldering the difficult emotional issues and challenging issues that families are facing in their homes at this time.

**Carol Regan:** Right. And you all -- in your remarks Bryan and Erin also, you all acknowledge -- mentioned acknowledging that everyone's dealing with their situations, some are just acknowledging and leaving the space for people to have that conversation is really important.

So for time, I'm going to go over to a couple scenarios we talked about that might really - - concrete example of what you were giving Bryan and yours to talk about how you might respond to some real situations that are going on now.

So let me just share one. Daniela has been caring for her father, Mr. Ramirez, who's a 75-year-old, who has dementia and they're in their home with added support from adult day program, which is now closed. Daniela is still employed, so she's working from home but she now has a responsibility for daily caregiving tasks along with her paid job. How can we help Daniela, and caregivers in general, cope with the stress of these additional responsibilities? Are there specific recommendations in particular here for caregivers of individuals who have dementia and maybe behavior challenges?

So let me start with you, Bryan. Can you talk about this? Yeah.

**Bryan Godfrey:** Yeah. And this is something that of course is similar to the case study that I've presented except many of you were probably wondering, but what if the person has dementia? And that's kind of what we're adding in here, so.

The same thing kind of applies in the beginning when we're trying to have empathy for the caregivers' position, trying to understand the exact needs of this dynamic, this family situation knowing the resources and being able to provide them in a way that's effective and targeted to the person that we're approaching and really understanding that change and acceptance of all this is going to take time. A lot of times it takes families a long time to sort of wrap their heads around the idea that someone has dementia, to accept that as a diagnosis, and then further to understand how it's going to change how they think, how

they act and how we need to interact with this person. These are all things that are very, very difficult and may not be in line at all with how families have lived up to this point.

For example, if a family is very accustomed to deferring to someone in authority, but this person now has a cognitive impairment, this whole family dynamic is going to need to change. And this is something that certainly won't happen quickly. So I think -- obviously we can provide what support and guidance we can. I think it's important to be able to link families with other supports that they can access especially in times of crisis when a new dementia behavior sets in or a new argument starts and they get away from that but they're just not sure what to do.

So connecting with folks -- the folks with resources like the Alzheimer's Association 24/7 hotline, whatever it might be. There's actually a lot of local groups in many places where you can actually have a consult with a fellow caregiver or a community leader who can provide some education and understanding. Support groups can be really helpful, all sorts of things. But really understanding from the doctor, what kind of impairment is taking place here and then using all of your resources to figure out -- okay what do we all do now?

**Carol Regan:** Thank you, Bryan, really helpful. And, Kathy, I just wanted to bring you into it briefly, because I know recently you were chairing the dementia -- a dementia care panel on that, so is there anything else you want to add about to what Bryan shared about helping families with caregiving responsibilities for people with dementia?

**Kathy Kelly:** I think oftentimes families really could hear that they have permission to ask for help, particularly from other family members as well. But it's not -- you can't just generalize the help. I think if you're able to work with the family caregiver to ask what kinds of specific tasks. So there -- we fail to see the help that's around us sometimes, but they don't know exactly what it is that you need. So if you can work with, get permission to the caregiver to ask for help and then work on specific tasks -- I'd like two hours a week so I can go take a walk or I want -- could you do a meal a week? Or -- very, very specific asks -- help the others around you understand what it is that you need and people want to help but they want to know how to help.

**Carol Regan:** It's really helpful. Thanks, Kathy. Thanks, Bryan.

So let me turn to another kind of situation scenario. So let's talk about Mrs. Young. So Mrs. Young is a woman who has multiple chronic conditions and she recently had a fall. She currently lives at home and receives support from a part-time home care aide, as well as her sister Miri. So Miri recently moved in with her sister to help care for her. And so now after the fall she needs a new care plan to address her changing needs. So first up -- let's -- what would you -- how would you developing a care plan for Mrs. Young, which also addresses her sister's needs -- Miri's needs? And how would that differ than sort of an in-person approach? This is now being done sort of virtually. So, Erin, let me turn to you first to address that. How would you approach doing a care plan?

**Erin Emery-Tiburcio:** Sure. So it seems important to identify whether a video or telehealth options are available, there might be multiple options for physical therapy, occupational therapy, the team. to be able to get involved and so understanding what options are available is really important.

I think one of the things that the fall highlights as well is the impact of trauma. And one of the things I'm seeing clinically recently is those who have a history of trauma are really getting triggered by COVID. And so a new fall and the new experience of helplessness and hopelessness with regard to that experience may be triggering old elements as well. So assuring that we are not only looking at what the new needs are, but are there historical issues like trauma that may be impacting what's going on right now. So the case manager who's getting involved to try to set up that new plan might need to coordinate and organize all those services and kind of keeping an eye toward are there any historical issues particularly trauma that may be impacting what the needs are currently.

**Carol Regan:** It's really helpful. Again it goes back to really assessing what that person's asking, no questions listening. Thank you, Erin. Bryan, do you want to give us some additional insight from your perspective as a clinical social worker at a geriatrics clinic?

**Bryan Godfrey:** Yeah, definitely. Thank you. I think a lot of the assessment that we would do would be very similar, whether it's done in person or over the phone. But there are unique challenges whether it's a phone or a video visit that present when we're doing telehealth.

So of course a lot of what we'll be doing is the same, we're still being curious, we're still working to establish that rapport in a way that we're open to hearing what's going on, what their ideas are and what they're perceiving as challenges. We're showing that we're listening, that we care, we are normalizing the experience of all the frustration and uncertainty and loss of control and we're empathizing with that.

And then when it comes to addressing the challenges of lack of in-person communication, we're also frequently using things like summary and checking our understanding, stating back to the person -- okay, so what I'm hearing is -- and actually give them a little summary of that to make sure that you've understood and give an option for them to correct you if needed. Also using teach-back. Many of you are probably familiar with this idea that we ask at the end of the call -- okay, so what have we talked about today? Or what did you understand about what I just said? And see what they're able to actually give back to you. That might give you a good sense of what's been understood or not understood.

**Carol Regan:** Great. Thank you, Bryan. And now just to wrap up on this scenario because it seems really timely and important here, what are the additional considerations for virtual approaches to supporting caregivers? We talked a little bit earlier, mentioned some technology and Kathy, you've done a lot of work on this, could you address this issue about sort of virtual approaches to supporting caregivers?

**Kathy Kelly:** Sure. It's important to ask what kinds of technologies they're using at home, we do this as a standard measure that we ask; what's available to families. If in fact families are not connected and many aren't, there are ways in which you can help that connection happen.

It might be a little disjointed at this particular time, I have done this for friends of mine, but we developed 2 tip sheets actually for this program on internet services for low-income adults that gives you advice of where to go to find those services in your community. It's nationalized in terms of its availability, and its availability may not be in all communities to be sure, but with this you'll be able to see what is available in the communities if there is no internet connectivity available for families to use. And then there is a question, of course, after looking at internet services which can be fairly low cost as low as \$10 a month for basic internet services.

But it comes to the equipment issue and the training issue for older adults and there's a number of different ways to approach this. There's lots of different types of products out there, there's a number of communities that have -- that refurbish a product to turn around and either provide them for free on loan or at low cost. You can find those kinds of options in your community and might address some ways in which to search for them in your local area.

And in training, it is pretty broad. I think most senior centers now offer basic internet skills training. There are some programs that will use volunteers to go into the home, maybe not at this particular moment but in the future. I think what we're going to find, as a result of COVID, is that we view internet connectivity as a health utility because so many of these kinds of interactions within the health systems can take place and are being more broadly accepted and there's payment sources for that. So it's important that we are able to bring people into using these services in their everyday life, not just during emergencies.

**Carol Regan:** This is so helpful and I'm so glad you've done that tip sheet, because I think as we know so many people particularly as we're focusing on people who are dually eligible for Medicare and Medicaid are low income and having that resource for them and their family caregivers could be a game changer.

Gee, thank you all so much for these important discussions around a couple different scenarios we've had in your ongoing commitment to working with family caregivers.

Now for all of you on the phone, there's many, many of you. Let me turn it back over to Alana, then we can open it up for your questions and answers for the panelists and Alana will direct questions to each of the faculty, so thank you.

**Alana Nur:** Thank you, Carol. And thank you so much, Erin, Bryan and Kathy for sharing all of your valuable information so far. We now have a few minutes for questions from the audience. Thank you to everyone who has already submitted questions. If you have additional questions, please submit them using the Q&A feature on the lower left of

the presentation screen. You can type your comment at the bottom and press Submit to send it.

We'll get started with some of the questions that we received already. So thank you to everyone for submitting them. Let's see, we've received a number of questions from folks who heard from Kathy and all of you have mentioned wellness check calls for caregivers. Can you provide some examples of the types of questions that you might want to ask caregivers when you are reaching out? Kathy, maybe I'll start with you since you mentioned them.

**Kathy Kelly:** Okay. Yeah, there are a number of examples of wellness calls that are sort of floating around. These are not what I would typically say are standard kinds of measures, in other words they're not -- anyway so we start out with just saying -- how are you doing? Are there particular issues that concern you today? We also ask about food security issues, whether or not they lack transportation to get to doctor's visits if that's needed, do they need consumable supplies.

So we need to know things that we may not normally ask in the course of our check-ins because we've referred to services or linked them to services in our prior conversations. But those may not be available at this point and so we're getting these listings of needs for the family. Those are the three biggest ones, besides just asking how are they doing, is everyone well in your house, do you need any more information on COVID? And then food, transportation, and consumable supplies, and do you have a way to get your medication; either someone can pick them up for you or you can have them delivered or mailed to you. So those are sort of the standard questions that we would ask.

**Erin Emery-Tiburcio:** This is Erin, if I could just jump in really. I might suggest that people also ask about mental health in those checks, both for the caregiver and the care recipient. And whether or not you do a full PHQ-9 or GAD-7 to consider how's your mood been, how's your motivation been, and to be able to provide referrals.

**Alana Nur:** Thank you, Erin. Bryan, anything else you'd like to add?

**Bryan Godfrey:** I just like to emphasize whenever you're asking about a need, our culture tends to downplay asking for help. We tend to ask people to be independent as a culture. So I find it's often helpful to start by normalizing the experience or the need for help and then asking for -- if they need assistance from there. So for example, not just do you need food but in times like this a lot of people have trouble getting to the grocery store. Do you need any food?

**Alana Nur:** Great, so important. Thank you, Bryan. And this question, I think I'll start with you. We received questions from folks who have caregivers who may seem to be feeling stress or isolation at this time, but may not initially feel comfortable sharing their feelings. Any suggestions for how one might approach that type of conversation?

**Erin Emery-Tiburcio:** Sure, so I think what Bryan had just emphasized in terms of normalizing can go a long way. And to be able to say caregiving by itself as an incredibly stressful situation that most caregivers would really benefit from some professional

support. And now that we are in COVID, I would suggest that every caregiver could benefit from some professional support. So really normalizing that this is incredibly stressful for all of us and that there are supports available and just ask if they'd be interested in talking with someone about the stressors. Without necessarily pathologizing into depression, anxiety or other things that people might find stigmatizing, but just to say you know stress is really high right now across our entire world. And my goodness, you have that added layer of caregiving stress on top of all of that. I would really suggest that you might talk to somebody, what do you think?

**Alana Nur:** Thank you, Erin. Kathy or Bryan, anything you all would like to add?

**Bryan Godfrey:** When it comes to mental health support, it depends on your relationship with the person obviously. But if it's someone you have rapport with, you can sometimes self-disclose and that can be helpful too. You can say something like I've been really worried and stressed. And I have no problem disclosing myself when I see a therapist and I find it very helpful. I would recommend anybody do the same if they're feeling like they're under a lot of stress. And sometimes, that has gone a long way to sort of normalize and humanize this whole experience of needing help and getting it.

**Alana Nur:** Thank you, Bryan. Bryan, I'm going to stick with you for another question, so whether folks with caregiving responsibilities, they're changing or not there's often situations where you may share caregiving responsibilities with more than one caregiver. Certainly in times like these as well as in normal times, there can be tension. Do you have any recommendations or suggestions for how to support caregivers who may be sharing responsibilities and experiencing some tension?

**Bryan Godfrey:** Definitely, and it's such a common issue. One of the most common things that I'll hear about from a caregiver is that other family members are not pulling their weight as much as that person would like. And so, I think that it's important to remember number one, what Erin was talking about earlier that the only thing we can really change is ourselves and our own behavior. We can't necessarily change someone else's willingness to participate or how much they're participating.

Now that doesn't mean we can't ask and I do think that there is very often not very good communication between family members. And this is often a very long-standing pattern that's hard to change. Sometimes it can be helpful to get folks to engage with a therapist if they're willing to. So the therapist can help them explore how to either potentially approach this person and make a request in a way that's likely to be heard or whether it's best to just radically accept that the division of labor is unequal and we have to live with that.

I think something else that's important to keep in mind is that people will contribute in different ways but often not until they're asked directly. And anyone for example who's ever been grieving and someone has said, "Call me if you need anything." We're not likely to take them up on that because we don't want to be a burden and there's lots of complex dynamics there. But if someone just happened to bring us a meal, we're not likely to turn that down. So identifying other people and how they might contribute in a

way that doesn't feel burdensome to them and then asking them specifically to do that could be helpful. We often don't want to ask, we feel like it should just be given. But in truth, we have to ask for the things we need or we just can't expect them.

**Alana Nur:** Thank you, Bryan. Erin or Kathy, anything that you would like to add?

**Erin Emery-Tiburcio:** I think Bryan's answer was fantastic.

**Kathy Kelly:** I don't think so. Yeah, great answer.

**Alana Nur:** Kathy, so I know you've been working with health plans and we have a number of folks from health plans in the audience today. We're serving dually eligible members and their caregivers. What recommendations do you have for how health plans can best support caregivers at this time?

**Kathy Kelly:** I think health plans need to recognize caregivers on a routine basis. Many also have caregiver notations in their case notes -- case files on the patient. So it's important to -- I think to reach out on these wellness checks. It's also I think important to tap into the community network. If there's any calls that are going on, coordinating calls that are going on within the community, to really understand what resources are available not everything is available at this time because it's not usual time.

So to really understand and connect with the community, I think is really important. Then you're able to better respond to families and give them more of the on-the-ground, what's available, what's not available, instead of your usual and customary referral sources that may or may not be operating with business as usual. That can be particularly frustrating for families but understanding what resources are available, being able to expand the resource lists that are provided here and elsewhere to families at this time is sort of an -- it would be incredibly valuable.

And if you're able to do these kinds of check in particularly with cases that are very complex or have some sort of underlying risk factors that are involved, it might be important to check in with those as well -- those individuals as well.

**Erin Emery-Tiburcio:** This is Erin. I would also love to just add to that, to advocate for health plans maintaining access to telehealth even after COVID. One of the things I hear from caregivers so often is, "I can't come see you because I can't leave my loved one at home." And so having this unprecedented access to telehealth is an incredible boon for caregivers, so I would advocate that health -- one of the things health plans can do to make a big difference is maintain that access even after COVID.

**Bryan Godfrey:** And this is Bryan to quickly add on as well. One thing health plans can really consider is their reimbursement rates for the different types of telehealth. Currently, many plans will reimburse a phone call at a much, much lower rate which means a lot of providers are not interested in pursuing them. But at the same time, many patients don't have access to reliable high-speed internet that's required for a video visit. So anything we can do to help make sure folks get the care they need and it can be fairly reimbursed would be really helpful.

**Alana Nur:** Absolutely.

**Kathy Kelly:** Can I just add one point on the -- from the community-based side? That there's an implied standard of the telehealth visits from a healthcare perspective because they are contracting with platforms that are HIPAA-compliant. On the community side, if you want to do these kinds of visits with sensitive information, you must make sure that the platform that you're using is HIPAA-compliant. We talked about it as being all one thing but having the experience of reconfiguring our community-based organization and others throughout the state of California, you just have to be mindful that we're talking about a different level of security on these video calls as there's sensitive information that's being shared.

**Alana Nur:** Great, thank you, all. On that note, Erin, you mentioned -- I'll start with you. Being able to hold these telehealth sessions now with caregivers and particularly you've all mentioned that some of these may happen over the phone and certainly having a phone conversation is quite different than an in-person or even a video conversation. Do you have any recommendations for best practices to maintain connection or have a good positive conversation over the phone?

**Erin Emery-Tiburcio:** It's an interesting question and there are actually some resources out there about identifying specific ways to do this over the phone. I think one of the things that can be helpful is to say if it's if it's phone versus video. Video I actually find incredibly helpful, because then they cannot only see my patient but also see their home and get to know a little bit more about the context. So that can actually be sometimes even better than an in-person visit because I can get to see the home.

Via telephone, I think it can be helpful to sometimes say, "I can't see your face, can you tell me what -- a little bit more about your experience? Can you describe what you're seeing? Can you describe a little more?" And to be able to be explicit when there is silence to -- silence can feel very different on a phone than it can in person. And so to be able to acknowledge, okay so -- we were just silent here for a minute, can you tell me a little bit more about what's going on? And so inviting people to use words more than we might rely on facial expression. And it'd be really curious actually about -- Bryan's done a fair amount more of this. I'd be curious, Bryan, what you would say.

**Bryan Godfrey:** Oh goodness, I actually got distracted reading the comments. Could you fill me in on the topic?

**Alana Nur:** Talking about tips for telephone and how to most effectively use telephone.

**Bryan Godfrey:** Definitely, thank you. I think some of our previous comments apply well to this and kind of like we were saying really just double-checking, understanding, making sure someone can give back. Yeah, it's definitely a challenge when we don't have the face-to-face and sometimes whether it's phone or video, we just feel like we can't get the information that we need. Sometimes, following up with other people who have more of an in-person connection to the person, whether it's a caregiver, someone else who's

living with them, or a family member that just knows them really well. Tapping into that as a resource for information can be really helpful. Thank you.

**Alana Nur:** Okay. Thank you, both. I want to give some time for you all to share any final words that you'd like to leave with the audience members today. Now we're wrapping up our Q&A portion of the webinar. So, Kathy, I'll start with you. Anything -- other topics that we haven't been able to touch on that you'd like to share some insights with the audience.

**Kathy Kelly:** I think there's one that I really actually meant to mention earlier before that we have -- we also need to be mindful of, because of all of the extra stresses that we have been discussing, and there might be different family configurations now living in the home, and there might be more people. And just might -- or there may be just a dyad in the home providing care that we have to be mindful with all of the stresses that we're discussing that we also pay attention to the possibility of elder abuse and be mindful that we need to be able to probe and ask the questions that might get at the various risk factors that might be present. And to make sure that we have reached out to the Adult Protective Services Community to find out how they're functioning at this time. And what their staffing levels are at this time to be able to make adequate referrals if in fact, the risk factors indicate that there may be some other kinds of more serious issues going on in the home.

That's just one but I also just want to leave this message behind which is that, we all are learning as we're going along how to deal with this crisis. And we have been able -- I think many of us have been able to pivot really easily into alternate ways of delivering services and touching base with individuals. But we're really learning and as this moves along, the needs are going to change and so to be able -- to be fluid and gather as much information and come back and talk about what's going on and sort of the broader scope between the individual clients and the community allows you to use that information to better plan or find additional resources or information that would be helpful to families or to your staff.

So we're all we're all in this together, we're all learning together how to deal with this pandemic and so we need to give ourselves permission not to be perfect, that we're not going to get everything right the first time. But with all of the different resources that you've been provided today and with the help of your own communities, I think we can move forward and do as best a job as we possibly can with these difficult situations at this difficult time.

**Alana Nur:** Thank you, Kathy. Bryan, I'll go to you if there's any other final words you'd like to share.

**Bryan Godfrey:** Yeah, thank you so much. As you know, I've been engrossed reading y'all's questions. There have been so many of them and I feel bad we haven't been able to get to each individual one. I think one thing that helps me a great deal as a social worker was to remind myself that the ultimate onus for solving a problem never lies with us. It can't, it's not our problem to begin with. And we all mean well, we all want to help

and that's all very admirable. But at the same time, we need to recognize that these problems don't belong to us and ultimately we can't be the one to solve them. All we can do is offer thoughts, and advice and resources. And I think we can do that very skillfully if we focus first on not solving problems and fixing things but really connecting with the person. Getting to understand what they perceive as their barriers, reminding them of their own strengths, and then helping them to creatively approach this problem, offering ideas and ultimately letting them figure things out for themselves.

**Alana Nur:** Thank you, Bryan. Erin, I'll leave the last word with you.

**Erin Emery-Tiburcio:** Thank you. There are two things that come to mind. Number one is that this is a time where many people are being taken advantage of with scams and so there are so many out there that people are nervous about answering the phone, they're nervous about talking to people as we're talking about doing these assessments over the phone. So I would encourage people to very clearly identify yourselves, who you are, what your name is, what organization you're with, any information you already have about who the family is, so that they can be really clear and confident that they're talking to someone they should be talking to.

And number two, that kind of builds on what Bryan was just talking about that we don't necessarily have to solve the problems for them. If we acknowledge that from a strengths perspective that these are people who are incredibly resilient and pointing out their resilience, identifying what's worked in the past, and identifying what resources they do have. We've talked a lot today about the stresses and things that are going wrong and needs, and I think it's easy to forget that caregivers are also incredibly resilient and have amazing strengths. And reminding people to tap into those strengths at this time can also be incredibly helpful.

**Alana Nur:** Thank you so much, Erin. All right at this time if you have any additional questions or comments, please email us at [ric@lewin.com](mailto:ric@lewin.com). I'd like to bring to your attention the next slide where we have additional resources we have developed to support plans and providers during these times. You'll see the links here on the screen and then the chat window on the left-hand side of your screen, as well as on our website. First, with help from the speakers, we've developed this slide that contains resources for caregivers, specifically for stress and isolation. And second, we've compiled resources for providers, health care leaders and caregivers for emotional support, coping and managing stress during COVID-19. You'll see that link also on the slide presentation and in the chat window.

The slides for today's presentation, a recording and a transcript will all be available on the Resources for Integrated Care website shortly. Thank you, everyone so much for joining us today. Please complete our brief evaluation of our webinar so that we can continue to deliver high-quality presentations. If you have any questions, please email us at [ric@lewin.com](mailto:ric@lewin.com) and follow us on Twitter @integrate\_care. Thank you again, everyone, so