

# Coaching for Caregivers: How to Reach Out Before You Burn Out

## Webinar Transcript

Laurie Fink:

Good afternoon, everyone. The Quality Insights Quality Innovation Network team welcomes you to today's webinar, "**Coaching for Caregivers: How to Reach Out Before You Burn Out.**" My name is Laurie Fink and I'm the Communications Specialist for the Improving Care Coordination and Quality Initiative.

Before we get started, I would like to take a moment to review a few housekeeping items. First, all participant lines have been muted and will remain in a listen-only mode during the presentation. There will be a question-and-answer session following the presentation. If a question comes to mind at any time during the session, please feel free to type it in the Chat or Q&A Box, which can be found on the right of your screen. If your chat box is not open, please look at the upper right-hand corner of your screen for an icon that contains what looks like a speech bubble and the word 'Chat'. Click on that and that will open up your chat feature.

For those of you using a Mac, your chat icon is located at the bottom right-hand corner of your screen. All questions and comments that are entered into either the chat or Q&A will be addressed at the end of the session. Please note that this webinar is being recorded and a recording, along with the presentation slides, will be posted on the Quality Insights website later this week at [www.QualityInsights-QIN.org](http://www.QualityInsights-QIN.org). Both resources can be found under the Events tab as an archived event.

I would like to now introduce you to our today's speaker, Yosaif August. Mr. August is a certified life coach, award-winning healthcare innovator and author. Twenty years ago, due to his own experience as a hospital patient and as a significant caregiver for his parents, he made a radical change in his career. He left the New York City-based management consulting firm he and his wife founded and had co-managed, and founded Healing Environments International, to develop innovative ways of improving the experiences of other patients and family caregivers. One of those ways was Bedscapes, a multi-sensory system for helping to provide a peaceful bedside environment for patients and their families.

Bedscapes swept the International Healthcare Design Awards in 1996 and August traveled throughout the US speaking to healthcare executives about the importance of creating a healing environment of care. He was committed to generating clinical outcome studies that would demonstrate the benefits of these environments. He was awarded an NIH research grant and served as a consultant to Johns Hopkins on two published studies, one of which had been cited in research journals 296 times. He's also the coauthor, with Bernie Siegel,

of Help Me to Heal, published by Hay House. Mr. August is currently on the second year of a national speaking tour for the Christopher Reeve Foundation's Caregiver Day program. The focus of these presentations and the focus of the presentation today is a message of his most recent book, Coaching for Caregivers: How to Reach Out Before You Burn Out.

Without further ado, I will hand the presentation over to Mr. August.

Yosaif August:

Thank you so much, Laurie, and also to Mary Ellen Jacobs, who's also helping to facilitate today, and Dr. Miller, for inviting me to participate, and very, very importantly to all of you. I have a feeling that carving out an hour out of your day is not an easy thing to do and to invest in this. I'm going to do my best to help make it worthwhile. We're quite a powerful group. I saw the list of people who registered. Not only are we people from eight states and on both sides of the country, but we're people in fairly significant roles in the organizations that we provide. I love speaking with you because you are people who really have high impact on the people that I'm very dedicated to serving, namely the family caregivers. I'm really going to be asking you to be looking through as we're going through this to think about how you can use what I'm presenting to work through your staff to help family caregivers, who are so critical to the well-being of millions and millions of people and certainly hundreds of thousands in the areas that you work in.

If we can imagine, what would happen if one day, tomorrow, family caregivers were taking a day off, we got something we want to do. We're going to go out and have a massage and we're going to go to a spa and we're going to do this. We don't even want to go there. What would happen in this country if caregivers took the day off. It's hard to imagine. I don't think we really need to do that very much. Our job is to ensure that today's family caregivers don't become tomorrow's patients and clients. What I'm presenting today is around how we can help family caregivers who so significantly are facing challenges. I call it the fog of overwhelm where people feel like there's just no way out of it.

Today is going to be about how to empower family caregivers. One part is motivation which has to do with perspective and possibilities, how they see, where they are, and what is possible, and information around systems, strategies and some resources and some tools they can use. You're the messengers. I'm asking you to think through, as we're going through again, ways that you can translate this and get this in front of family caregivers. It's also for you. We're all civilians here.

I was at a New York Academy of Medicine meeting a few months ago and there was a presentation by Johns Hopkins people. They realized that so many of the providers in the Johns Hopkins health system are family caregivers themselves. They go home after a very long intense shift at the hospital regardless of whether they're an executive or whether they're a custodian or whatever, and they're taking care of somebody. They have a program called 'Called to Care'

and it's about supporting everybody. A lot of what I'm talking about may have implications for you personally.

I would love you to share your insights as we go along or at the Q&A point. Let's just go forward here. These are some of the topics that we'll cover, some basic truths about the situation of caregivers, challenges that they face, and moving into the beliefs that people have. Beliefs either help to move us forward or they hinder us. That's really run how we act out in our lives, so re-looking at those. Then, focusing in on needs, particularly practical needs that caregivers have, and there are some ways to help them break those things down into ways that people can then step forward and assist them. We'll then talk about the very important issues of privacy. We have an animated video that I hope you will enjoy that talks the part of that. Then we'll be looking at some techniques and some resources that caregivers can use. Caregivers all over the country are using these and I want to share them with you.

Let's get right to these truths. This is obviously clear, that nobody can do it alone, at least not alone and continue to have a reasonably good health and well-being. The importance of having a network of support, I think, it's a very obvious thing that people can't really do this in isolation. The next point, about helping helps the helpers. I wonder if you're familiar with the research, the growing research around altruism that our immune systems are strengthened when we give to other people, when we provide to people, when we reach out to other people. The architecture of our neuro system incentivizes us and rewards us when we do good and that these hormones are released, neuropeptides are released. There's a lot of rewards in it for the helpers.

I think we may have a lively conversation in some way about it, we're not talking here, but when I speak around the country, I ask people in a room, "How many people here believes that caregivers live longer?" Not a single hand goes up in the room. Then I asked, "How many people here would love to believe that caregivers live longer?" Essentially, everybody puts their hand up. I'd like to share a little data here with you about this very issue. David Roth at Johns Hopkins, he's the director for their Center for Aging and Health, he did a study with a huge sampling. It was 3,503 family caregivers of people who suffered stroke and a comparable group of non-caregivers. He found that the caregivers were 18 percent more likely to live longer.

Now, these were very well-matched groups, all these multi-variant analyses that they do, and do that. Even, by the way, with that, the caregivers group happen to be more depressed. Even with their depression, they live longer. Now, depression doesn't help people's health and we've done something about that, but that was a very, very significant finding for a group of caregivers who, as you can imagine, caregiving for somebody who suffered a stroke is a very, very intense, significant and usually long-term kind of a role.

There's another track here about living longer. It's the research that came out of the study of purpose. I originally discovered this from Paula Span's column in

the New York Times. Dr. Patricia Boyle in Chicago studied people who scored high on purpose, they have an instrument that they use to measure purpose, and found that people who were high on purpose were 2.4 times, not percent or what have you. This is 2.4 times less likely to develop Alzheimer's disease and that also is likely to develop mild cognitive impairment, which often is a precursor of developing Alzheimer's. The other statistic here is that they half the mortality rate.

This is pretty amazing data. My sense about how does purpose come in here with caregivers, it's very obvious that people who are caregivers have a high purpose because they have it directly. It's not even something out there somewhere. Their purpose is to help keep their loved one alive and as well as they can. I'd like to consider that. I think it's really important data even if it is counterintuitive. With all these added longevity, there are real challenges that caregivers face, being exhausted and isolated and being stressed out and being either depressed or in despair. Caregiving is not the only way to develop these, but caregiving certainly induces this in so many caregivers. Those are the ones that reaching out is a very important way of helping to take the edge off these.

Let's go to the next slide here. Actually, I'm going to go back for a moment. In my book, *Coaching for Caregivers*, we're moving into the area of beliefs that I would have a little exercise. I wish we could do this with a back and forth questioning. How about a little surprise quiz for everybody here, multiple choice? I'm going to ask you some questions and you just think about what your response is. Question one. People who ask for help are wimps, self-indulgent, wise, or misguided. Second one. If I reach out for support, I will, A, open up the floodgates and be overwhelmed; B, open up the possibility of getting what I want and need; C, undoubtedly be disappointed; D, wasting my precious time and energy.

A few more. Question three. People I reach out to will mostly, A, feel relieved to know how to be helpful; B, consider me a pain in the butt and a burden; C, feel uncomfortable and resentful; D, be embarrassed. One more. The right time for me to reach out is, when things are getting better; when I have more on my plate than I feel like I could handle; anytime that it feels like it's the right time for me; or B and C, both. That's when I have more than I can handle and anytime I feel it's right.

I'll be glad to send this to anybody who emails me and request it, if you want to use it or modify it or play with it, or what have you. This gets us into the area of self-limiting beliefs. These are beliefs that I believe holds people back from getting what they and their loved one want and need. I'd like you to look at them and see if there's one that you believe that your caregiver clients would subscribe to. It's important that beliefs that we become aware of them. As we become of them, then we can say, "Does this belief really support me? Does it really work? Is it really true?" Then we have a chance of doing something about our frame of mind. The flip side of that is, what are some beliefs that help us feel loved and able to feel capable and being able to move forward.

If you would take a look at these. Caregivers, like all of us, have needs on many levels. In my book, I have some processes that I suggest that people use to go through each of these levels. We're going to focus on the practical now. I particularly urge people to take a look at what kind of needs they have on a spiritual level, because finding meaning and whatever is going on is so critical to being able to get through those things and still have a life. Let's for now go into the practical needs that people have. When I mentioned the term 'fog of overwhelm', what I'd like to describe is when a caregiver is feeling like they have too many demands going on, too many decisions, too many deadlines, too many things that need to get handled that they're not able to really focus on what are the things that are most important to be handled right now, and what could be handled tomorrow and what could be handled a little later, and all the kinds of things about what their needs are.

One approach to that, and it's not a magic kind of pill, is to start breaking things down to what I call bites or one-hour tasks. I lived in Woodstock, New York for several years, the famous, notorious Woodstock. It actually was a very, very sweet, caring, connected community, but we certainly had that reputation from the Woodstock that didn't even happen in Woodstock. I was a volunteer in a program called Angel Food. It focused on delivering hot meals, home-cooked meals to people who are homebound who had HIV. What I did is I committed myself two hours a week and for those two hours, we lived on a mountain top and I would shut down my computer, get in my car, go pick up food from the place that produced it, and go deliver food to a few people scattered in the countryside. I will be back at my computer in two hours ready to resume my day. What I was able to do with that is, in my way, I made a difference in some people's lives.

That was something more than had I thought of what can I do people with HIV. It was way too big. Just the idea of unlimited commitment. Here I did something that was concrete. Did I change the world? No. Did I make some people feel better and more connected? Maybe so. It was wonderful. I did it for quite a while. What caregivers needs to be able to do here is to break things, start breaking things down into tasks that they need done. When I think tasks that needed to be done, the daughter needs to be picked up from soccer practice, somebody needs to mow the lawn, somebody needs to find a plumber, somebody needs help. There's some medical claims that need to be filed and maybe somebody can help with that. There may be a desire once a week to have some hot meal delivered so that the caregiver doesn't have to deal with that. Those are the kinds of things I'm talking about.

The second step is organizing them by who can do them, things that can only be done by oneself, and the caregiver needs to start thinking about that list could probably be whittled down in terms of what really needs to be handled by the caregiver, things that can be done by close friends and relatives, and things that can be done by a wider circle of neighbors and people in the community. What caregivers have to do is organize it themselves that can really enlist the support of one or two friends to reach out, to do some of that reaching out to them, and

choose the easiest way, the simplest way to get that out. In some cases, it may simply be word of mouth. In other places, it might be using a congregational list serve, or it might be the caresite, that I'm going to be talking about a little later today.

The last part is about, if it freezes up an hour of your time, you can use it in some way that truly is good for you. I asked an organization in New York City called The Caregiver Space, a nonprofit. It's a very good organization. There's a very good resource-filled website. It's called The Caregiver Space. I asked them to post a question to the people who follow them on the Web. If you had one hour of free time in the next week, what would you do with it? When I asked this question live, I get a universal response in the audience, "Sleep." Anything else is just only a small response. People would sleep. They're exhausted. It's one of those challenges that I mentioned earlier.

People can do that. There are other things. They could do anything. They could get a message. They could get a life coaching session. They could go shopping for themselves. They could go to a little spa. In any event, it starts to open up possibilities outside of their fog of overwhelm. Also, they don't have to do the whole thing. They could start with a few things in terms of these bites and try them out and see how they work for them. From what I've been hearing from people, it really does work.

This particular issue, I think, is a very important one regardless of how aware people are in terms of caregiving. Whether somebody is currently dealing with illness or they have a terminal stage illness, whatever the place they are in that trajectory, so often the caregiver feels like they cannot leave the house. Does that sound familiar to you, in your own life? Have you been in those situations? My suggestions here are really to take a look at that and see what it would take to allow you at some time to be able to leave the house. After looking at what your concerns are, maybe talking to other family caregivers and then consider ways of managing those concerns. There are people that you trust who might be able to do some of these things. Then there's what's the safest time of the day or the evening, where the level of need or demand is lowest, to consider those, and what's the safest amount of time to take leave, to just be able to plan it out in that way. Start small just like with the bites and the action, trying it out in a small way.

Now, these might not sound like rocket science, but most people don't do these things. The feedback that I have gotten over the last few years, these really work for people and they work for people because they're not some kind of alien terminology or what have you or a new model. These are just simply slowing down, stopping, taking a look at what the situation is and changing our perspective from besieged to one of being able to be instrumental and seeing possibilities.

Here's a needs chart. There's one of these in my book. They're a [inaudible 00:26:56].

Laurie Fink: Could all just please give us a moment here? We'll try and get back on track.

Yosaif August: What's that? Hello.

Laurie Fink: Hello. Sorry, Yosaif. We couldn't hear you there for a little bit, but we're hearing you again now. Please continue.

Yosaif August: Do you know where the last place was? Did we go over the needs chart or ...

Laurie Fink: You were just starting to talk about the needs chart.

Yosaif August: Just very brief. This is in my book and I would be glad to also send out a PDF of this to people. It's a way of getting the needs of the caregiver and the members of the family up on the chart so that you could start looking at, if you were to reach out, which of these needs might be ones that you could delegate to other people. The caresites, there's a category of three websites that caregivers can set up. I'll talk about them further on in this presentation. These are websites that include a calendar where you can post things that you need and it allows you in a very seamless, effortless way to put tasks up that you need people to handle. People who you've invited to participate in your caresite, they could sign up for them and they don't have to call you, email you, or what have you. They just sign up on the calendar and things get handled. It's really quite wonderful.

Asking for help, this is coaching that your staff can do for caregivers about how to put out their needs in their most positive, assertive, not aggressive, but aggressive, not apologetic kind of way, being clear and offering people opportunities to be helpful. Remember what I was saying about helping helps the helpers. These are offering people opportunities to strengthen their immune system. It's good for the people who are being asked to help. Asking for it unapologetically, these are things that you know that go along with assertiveness. Let yourself receive. That's a big deal for a lot of us.

I invented a syndrome. In my introduction, I mentioned that I was involved in some pretty intense, significant, and rigorous research with Johns Hopkins, so I know what research really means. I did something at the total other end of the spectrum. I was on a train when I was in the process of writing my first book with Bernie Siegel. I got this idea about receiving or giving and I asked the woman in the seat next to me, did she think that most people have more trouble giving or receiving. She didn't even miss a beat. She said, "Receiving, of course." Out of this significant database, N equal 1 here, I invented RDD, receiving deficit disorder.

It's something that so many of us have, that no matter how much we give to other people we have a hard time receiving. Fortunately, RDD is a very easy thing to get over, but it takes some work and takes some practice. If you think that maybe you suffer from this, a 12-step program is one that's useful, mainly

let yourself receive 12 times and by that time it should become somewhat of a habit. Let's have some more fun with this here.

Compassion and forgiveness. I can't say enough about them. People don't necessarily show up when and how and where we want them to. People have their own lives and make decisions for themselves. The more we could have compassion and forgiveness for them, the freer our psyches are to be lively and positive and living our lives. The more resentful that we are, that just burns up our energy unnecessarily.

Privacy. How important is privacy to you and your loved one? Just thinking of this personally, now, just consider what privacy means to you in your life now. We have all of these things in terms of using Google, all of our surfing, and all those things get tracked so much. We have that going on. What kind of things are important to you in your own privacy? Now, consider caregivers and what kind of things would be of importance to them in terms of that they really don't want the rest of the world to know about, because if they have people coming into their home, they're going to have those things potentially exposed. You know how they do housekeeping, on what their financial situation is, what some of the dynamics are between members of the family, all the kinds of things or ones that are in our intimate family personal lives, and some of which we really don't want the rest of the world to be in our business about.

Those are important things. When you're a caregiver and you're considering opening up your circle of love and support, those things can really be barriers. It's what I was talking about with that multiple choice test. If I think that the moment I opened myself up to this that I'm going to ask to suffer fools, it's not going to make it very likely that I'm going to want to reach out.

At this point, I am going to reach out to my collaborator, Laurie here to set us up for this animated video. It's one that I did with The Caregiver Space in New York. Here we go.

[inaudible 00:34:24]

Am I back on audio? Am I back on audio now?

Laurie Fink: Yes, you are.

Yosaif August: I apologize. It was the best of intentions and I was working it through. Apparently, people had trouble hearing that. Am I right? Laurie, is that right?

Laurie Fink: Yeah. I did hear a couple of people that they did comment they could see the video, but they couldn't hear the audio.

Yosaif August: By the way, you can see it. I have a YouTube channel on YouTube. It just says Yosaif August Channel. I have a number of videos there and this one is there.

You can see it and hear it at your leisure. I'm really sorry. We tried our best to make this happen. At the very end of after this woman was telling her unwanted advisor, "Thank you. We'll let you know if we ever need your advice," that kind of thing. She goes off. Somebody standing next to her says, "I'll have what she's having," the old Sally and Harry line. I'd like you to jot down, if you could hear it, what was she having. What was it that she got that this bystander admired? If you want to just jot down and just send them along in the chat what is she having. I'll see those in a bit, if we see them coming up on the chat.

I developed something that I called the declaration of interdependence, like how do we come about to be able to tell people how we want them to act towards us and what kind of attitudes that we want to have them come. Aren't they doing this huge favor? My response to this is, they are being very helpful and in a sense it's a favor, but it's also a favor to them to be able to do something good. We really owe it to ourselves, to our loved ones and to the people coming towards us to know what kinds of preferences we have about things like attitudes. This is also in my book, the declaration of interdependence.

It's basically saying leave your worries at the doorstep, reach step. We don't want your fear here. We don't want that kind of attitude here. There are things that are really good for my loved one and attitudes are just as important as the food and the medications and the other things that my loved one needs. If you can appear here, if you can show up with those attitudes, you're welcome. If you can't, then we appreciate and we'd appreciate it if you would maybe stay away.

The same thing with behaviors. What are the things that we prefer? For example, ask what we need right now rather than asking that I let you know when we need something. It's just not really helpful. "Let me know when you need something" is not necessarily a very enabling thing to do. Ask me if I want advice or information before offering it to me. That would have been something that that woman in the animation might use that advice. Ask me if I want to discuss our medical situation at this time.

If you run into somebody at the supermarket and you're the caregiver and you have a lot of things on your mind, and maybe it's a time for just even a little while, you had a chance to let go of your worry and your concern, and all of the kinds of problem-solving and scheduling and planning that you do. Somebody comes up to you and asks you how your loved one is, boom, you're back into that whole mode. If you were to say, "Good to see you. Could I ask you about this or would you rather not go there," it would be something that's unusual, but it would be really helpful to be able to do. That's the declaration of interdependence because we are interdependent.

We've been talking about perspective and about possibilities. Now, let's move into resources that people may use. Our inner circle, this is a natural organic circle that people have around them or not. Unfortunately, for a lot of people, that's really shrinking, but that's certainly a key place to start. Then you may

start to reach out to your congregation or you may have another spiritual path that's not a congregation, but whatever form that is or other list serves, you may fraternal groups, you may have interest groups that you're involved in that may have list serves to them and they're really, really useful things to tap. Community resources, namely your agency and ones that you're allied with. They're there and you exist to be helping people. It's important that people reach out to you.

Then there are the caresites that I mentioned. I mentioned the Christopher Reeve Foundation. If it has anything to do with paralysis, a spinal cord injury, they're an extraordinary resource for people. I have on my website a list of resources that I've gotten from the national caregiver organizations and I periodically update that list and I'm going to be updating it soon. Then there's an organization and an approach called Share The Care. They have a book that they develop. It's a manual. I highly recommend this approach. It's a way to help a caregiver and a family, organize a sustainable system of support around them. Basically, they gather this significantly large group of people, however many can be gathered, and they have a meeting which is really scripted and they developed a way to have a rotating leadership so that people do the things that they're most inclined to do, that they really like to do and nobody is in it for more than they want to do and for any longer than they want to do.

Again, I checked them out on the Web. The state of Wisconsin has a large program. Hawaii has a large program. It's a community-organizing model. I have committee-organizing in my DNA. I really think that where we are at this point in our society, we need to start really rebuilding that Web of connection, and Share The Care is an excellent way of doing that. You may want to look at it and you may want to consider bringing them in to do a training for your staff.

These are the caresites. Virtually, anybody can set these sites up. I'm not a technical person. It took me 20 minutes to set up one of these sites. I mentioned to you how easy they are to use. I'll go over that in a moment. Here is the CaringBridge and there's CarePages. What to do is you set up a community, decide who's going to be in that community. That's the privacy issue, so you can have it to be really small, you can have an intermediary, or you can have it to anybody who happens to hear about your loved one. Then you invite people to come in and only give people the access to it and then you post things on the calendar.

What you can do is let people know what's going on, tell people what you need, and you can receive the help. You can also receive messages of love and support. It's a very, very useful method. I participated in many of these over the last few years for people that I care about. There's my book, Coaching for Caregivers. The first part of it is about reaching in and it's about issues like strengths and needs and privacy issues, and those kinds of things, and then how to reach out, some of the strategies that I've talked about here today. There's more. There are a lot of process because I'm a life coach. I develop processes for people to look at these different issues and I suggest that people do this in 10-

minute reads, because caregivers don't have time to go sit down and read a whole book, but 10-minute reads are a good way to do it.

These are messages to caregivers. Accept yourself, wherever you are is where you are, getting the clarity of what you need, breaking them down into those one-hour bites that I spoke about. Let other people help you do the reaching out. Everybody is a giver. Everybody gets something out of this thing as well as gives. There's much more support than one might imagine if you go through the kind of processes I described.

I would like to ask you to solicit questions now. Also, I like you to really be thinking about what you can do in taking what I've presented today and making that available to your constituency, to your clients by way of your staff, what kind of ways you can do that. Do you develop materials? Do you develop programs? Do you do trainings or what have you? My book is obviously a resource. I would be happy to consult on looking at how you may want to do that. Let's just get to the questions. I mentioned YouTube channel. It's Yosaif August Channel and you can see those videos, which I think you can also make available for your staff to use with their clients.

I love going through this with you. Let's see what kind of questions there may be.

Laurie Fink:

Thanks so much, Yosaif. At this time, we will begin the question-and-answer portion on the webinar. If you have any questions for Mr. August, please type them in the chat or Q&A box on the right of your screen. If you have already submitted a question during the presentation, it will be addressed now as time permits. Please feel free to type any questions you might have. I did want to share with you, Yosaif, when you asked at the conclusion of the video where the character said, "I'll have what she's having," and you asked, "What is she having," we did get some comments from our attendees today. I want to share those. The first was confidence in her decisions. Another response was creating a boundary. Another response was assertive but not aggressive, so being positive and not negative. Left the door open to talk in the future, but under her initiatives, not the other person. The final comment about that was, setting personal boundaries and asserting herself without aggression.

Yosaif August:

Yes, we are on the same page. By the way, thanks to my sister-in-law who did the voices. I don't know if you heard it, but thank you for those. Let's post some more questions here, or let's post some questions, because we haven't gotten questions yet.

Laurie Fink:

Here's a question. What's the best way for people to approach caregivers that they're concerned about without being intrusive or undercutting the caregivers' self-esteem and confidence?

Yosaif August: I think that's really an important question because the least you want to do is do no harm, and you can do harm by intruding. I think that the easiest way is to basically put that out and say, "I'm concerned about you. I love you. I care about you and I want you to help me approach me. Tell me whether you would like my input about what's going on and talk to me about it. Whatever your particular way is of engaging to people, even saying, "This seems a little awkward, but I want to be helpful and I don't know how to start that conversation with you. Tell me how." Those are the things that come to mind. It's the asking that's the most important piece. I think there's so much reluctance to come forward that people have because they don't know how to do it right. Even saying "I don't know how to do it right" qualifies you. Did that make sense?

Laurie Fink: Absolutely. We did have one of our attendees asked if you could talk a little bit more about trying to understand those who don't offer to help. That's often a hard topic to approach. How do you recommend tackling that issue?

Yosaif August: This is in the area of compassion and forgiveness. If they're not coming forward, this isn't about how to [inaudible 00:53:54] and pull them in, unless there is something where you really want to ask people, if you can clarify, that they know what you need and is there a way that they could do it. I just want to say that I have a friend who's the head of primary care, one of the major hospitals in New York. When he was ill, it was really something to him that people he would have expected to come forward backed away. People who he was astounded by came forward.

Part of that has to do with being a powerful, very brilliant doctor, so people have their issues about how do you come forward and whatever. It was really something for him about people who were in those categories. I do think that it isn't personal. People are not coming forward because whatever their issues are, they have those issues. They may come out ultimately in some way that you found out about. The most immediate way of taking care of yourself is almost like to pay forward with compassion.

Laurie Fink: We had another attendee ask for some advice on how to release some resentment when you asked for help and it's refuted by close family who refuses to assist.

Yosaif August: How to deal with your resentment. These are really great questions and this is a great one. I think there may be other opportunities that come up to try it again. The thing about the resentment, really, it's self-work to say, in the scheme of things, my sister, my brother, my aunt, my uncle, they should be coming forward here and they're not, and it means I'm going to have to do that much more, but somehow you're rather finding a way to make peace with yourself with that. I just wanted to throw out another thing. This is not resentment, but it's a way to maybe pull in some of those people who are reluctant, because that happens in almost every family. There's the good daughter. Often it's gender. That's the way it is and for some family, it's the good son. Too often, just the daughter. To use them to help set up a caresite or manage a part of the

caresite even if they don't live anywhere near you and even if you think they may be initially reluctant.

We had a friend locally here who had a liver cancer. He lived in Philly. His kid, the person who set up this caresite was in Berkeley. Somebody who handled one of the aspects of the caresite lives in Boulder, Colorado. Somebody was even in Sweden who handled one aspect. Then there were those of us who lived nearby and we could take him to treatments and make sure he had food. A not-so-helpful sibling might be able to be enrolled in something like that, without dealing with, "You should have come forward," and what have you, but to find a way to enroll them in something useful. Everybody wins.

Laurie Fink:

We're not seeing any more questions and we're almost to the bottom of the hour. Thank you so much, Yosaif, for all of the great tips and advice you've given our audience on caregiving. I want to thank everyone for joining us today. If you have any additional questions, we encourage you to reach out to your local Quality Insights Care Coordination team member or contact Yosaif directly. His email and website are up on the screen. Please note that we will post the presentation slides and the recording of today's session on our website. You will be able to access these resources at [www.QualityInsights-QIN.org](http://www.QualityInsights-QIN.org) under the Events tab as an archived event. There will be a very brief evaluation at the close of this session. Please take a minute to complete it. Your input helps us plan further programming.

With that, I'd like to thank you again for taking time out of your day to join us for this session. Have a great day.