



Davis Phinney Foundation  
Social Connection and Parkinson's with Dr. Al Condeluci  
April 15, 2020

Melani Dizon ([00:01](#)):

Hi and welcome everybody. My name is Melani Dizon and I'm the director of education at the Davis Phinney foundation. And I'm really happy to have you here today for our webinar on social connections and Parkinson's with Dr. Al Condeluci. Hi Al. How are you? Thank you so much for being here today.

Dr. Al Condeluci ([00:18](#)):

Now it's so good to be with you and all of 'em are friends the Davis Phinney foundation and all the folks that are, that are plugging in really from around the country.

Melani Dizon ([02:50](#)):

Okay. now let's get started with a little bit of a short introduction of the great Al Condeluci. I'm so excited to have you here. Al has been a leader in community building human services and inclusive advocacy work for the past 50 years here into PhD and MSW from the university of Pittsburgh and he holds faculty status at the university of Pittsburgh in the school of social work and the school of health and rehabilitation sciences. Al is the author of seven books and in 2018 he received the key to the city of Pittsburgh. I've never met anybody who did receive the key to the city. The highest civilian honor given to a community member. He serves as a consultant, advisor and human service coach is on several nonprofit boards and government commissions on the state, local and national levels. He helped found the and convenes the interdependence network and international coalition of professionals, family members and consumers interested in community engagement and macro change. Al, I'm really happy to have you here today about social connections and Parkinson's. I have to say it's pretty serendipitous. We had no idea when we scheduled this many months ago that we were going to be in this middle of a global health crisis and confined to our homes. So, the conversation today is probably more relevant than it's been in a long time. So, to get started, what is social capital and why is it important?

Dr. Al Condeluci ([04:11](#)):

Yeah, well, well thanks. Thanks Mel again for this opportunity and, and you know, we would have been planning and ready to get ready for a victory summit and in Omaha that that we obviously not going to be able to do in, in, in a face to face format. So, having this opportunity for a webinar and having the, the many folks really from around the country that are that are participating is, is really wonderful. It's it, it's another way we can stay connected because social capital really refers to the value that people reap from their connected relationships. And the term

social capital, the not term, I guess the phrase social capital was actually coined in 1916. It's the first time it actually appeared in the literature.

Dr. Al Condeluci (05:13):

And it was coined by a schoolteacher in West Virginia. His name was L.J. Hanifan and Mr. H Hanifan was, you know, was not just a teacher, but really a scholar and an observer of community. And one of the things that he discovered and all way back in, in that early era was that the kids in his school, the kids that he taught in the small little town in West Virginia, that they came from kids that built relationships did better in, not just in school, but actually did in life. These were the kids that in the community ended up, you know, becoming active in their community and, and, and, and good civic you know citizens. And they weren't necessarily the smartest academically, but they were really socially savvy. And so, he, he wanted to, some, he wanted to in some ways bring value to this phenomenon.

Dr. Al Condeluci (06:29):

So, he called it social capital that using the term capital meaning value, that the, the kids that, that were, were socially astute were more successful in their community. And so, he ascribed this term social capital now after it appeared in the literature in, in in 1916 for the first time, sociologist and academic scholars noticed it and really began to probe a bit more and start to explore it a bit more. And in the ensuing years, academically the, the, the, the term really became King of Vogue with scholars and the, the use of social capital as compared to you know, physical capital was really clear. The, you know the sociologists really wanted to show that our, our social networks and our social relationships or bring value to our life. Around 1990, the concept really was popularized in the, in the literature beyond the academic areas.

Dr. Al Condeluci (07:51):

And it started to appear in, you know, some just mainstream literature. And in the year 2000, a Harvard sociologist by the name of Robert Putnam actually really popularized the term and put it into the public square by raising attention with, with elected leaders to the, the, the, the potency of social capital. And once public leaders started to recognize that when people built relationships, not only that they value but their communities valued, that people solve problems more readily. People became more pro social who had relationships. They, they were more compassionate. They were kinder, more honest based on relationships. And so, Putnam see you observing this and, and really looking at it academically decided to popularize it and then to embed the concept of social capital into the civic square. And so, you know, he at the time really was became like a darling of not just politicians in the United States, but really politicians around the world.

Dr. Al Condeluci (09:21):

And so, the concept and the construct of social capital really began to take off in the public square. And politicians began to recognize that the more they could promote the building of relationships with the citizen tree, with their, with their constituencies the you know, the, the better society could be. So that's kind of a long-winded answer. They kind of moved it from this OBS observational, educational, observational, done by Halfin, and then it's intellectual development by sociologists that followed. And then the popularization of the concept in the, in the 1990s and in the 2000 with Putnam, bill Clinton really began to try to take concepts of social

capital and embed them into his administration. And I think subsequent presidents have looked at that. And, and I think the other thing that, that when Bill Clinton became introduced to social capital that really got him engaged was a George Herbert Walker Bush when he proposed his you know, he, he had his construct of stars.

Dr. Al Condeluci ([10:48](#)):

You know, I've, I'm trying to remember now the actual term that he gave to citizens who basically really did good things for their communities. And so, we see this construct kind of moving full force. Now let me just quickly add why it's important. It is both an internal and an external phenomenon. Internally, relationships make people better. They make them stronger, they come healthier, they make people more self-confident, more comfortable more self-assured. We, we, we get, when we build relationships, we get this sort of feedback of our viability as a, as a human being from other people that we have in our networks around us. So, it has an internal impact that's, that's phenomenal. But it also has this external impact in that it, it makes other people better as well. It, it makes us collectively better. So that's, you know, I mean, I think it's important both internally and externally for us as a society.

Melani Dizon ([12:11](#)):

Great. And so, knowing how important social capital is, and also knowing that we have a large prevalence of loneliness and isolation in the world today, what, how does that play in and what's the difference actually between social isolation and loneliness?

Dr. Al Condeluci ([12:31](#)):

Yeah. Well. Yeah, that's, that, that's really a powerful notion in actually it's where most of my practice has really been going. A Mel over the last two, three years. I've, I've, I've been writing about social capital and actually studying it since my introduction to the concept back in the mid-eighties. And, and one of the things that really became clear to me as a disability advocate. And, and by the way, let me quickly add for the listeners at the webinar that you know, I've been a disability advocate my entire life. Growing up in a big Italian family, I grew up with a cousin that had a down syndrome and saw how she was treated by people in community, how she was denied access and opportunity, how she was made fun out by people, how, how she was left behind, not by our family but, but in a, in a broader community way.

Dr. Al Condeluci ([13:37](#)):

And then as I got older, I really experienced from very personal sense the phenomena of Parkinson's when my dad was diagnosed with Parkinson's. And, and you know, as a family supporting my dad. And one of the things I noticed personally, both with my cousin as well as with my dad was that when disability occurs, whether it comes later in life like it did with my dad or earlier in life like it did with my cousin who was born with down syndrome, that people who had disabilities had marginally less social capital. And in my practice, a running an agency that served people with disabilities. I noticed this prominently that, that people with disabilities are oftentimes disconnected and, and have less social capital on, on, on the congenital side. With my cousin Carrie, she never built social capital with to begin with because she never really had access or opportunity.

Dr. Al Condeluci ([14:47](#)):

And with my dad, my dad, who was very, very active in communities, editor of the local newspaper, he was a musician, a well-known in our community. When his Parkinson's was diagnosed and dad started to show some of the symptoms the tremoring and you know, some of the facial freezing and, and whatnot. He began to pull himself out of the mix as well as other people began to abandon him. And when I say abandoned, I, I think, I don't mean it from a malicious point of view. I think the abandonment that, that people began to do with my dad was more around their uncomfortableness and their hesitation and their nervousness about, you know, how, how to, how to talk with him or how to engage with him. But, but regardless, his social capital started to diminish. And, and, and in my work with folks who experienced Parkinson's, I see this, I hear this from my, my, my colleagues and friends who work in the field.

Dr. Al Condeluci ([16:01](#)):

And, and so this notion of isolation and loneliness at the root of your, your question is really, really predominant in a disability arena. But that's not the only place. It's predominantly, it's also, it also is predominant in aging with elders, just generic elders. It's predominant with mental health conditions. It's predominant with folks in minority communities, single parents. There are other groups of people who are at risk of social isolation and loneliness. So let me, let me sort of describe them. Just quickly. Social isolation really speaks to the absence of a core group that you rely on for, you know, social nurturance and, and, and for human connectedness. So, when people are socially isolated, they're, they're really there, they're limited socially. Loneliness can unfold in the presence or the absence of social isolation.

Dr. Al Condeluci ([17:26](#)):

Give an example here. I, I don't really feel that I'm a socially isolated person. I have a, a large cadre of family friends that, that are really important to me that I, that I take really seriously, and I really look to nurture and, and, and work on. So, I, I don't feel socially isolated at all. However, when I travel, I feel I can feel lonely if I'm traveling somewhere like a, come to Omaha to do a victory summit. And I travel by myself and I get there. And even though I see my friends there, I still miss my family and I miss you know, my routines. And, and so loneliness can happen in the presence or absence of isolation. But isolation is really the toxic phenomenon. And, and actually Mel, it's so toxic that social isolation has been identified by our CDC and the world health organization and other public health entities as a determinant, a negative determinant for, for healthful mess.

Dr. Al Condeluci ([18:39](#)):

That it's, it's a clinical variable. It's actually a social variable that ripples into a clinical phenomenon that that really puts people at risk a health risk. And Putnam articulated in his work that actually social isolation can lead to death to premature death. And that there's example after example of how when you're, when you become socially isolated you can be at, at serious risk of literally dying life expectancy data is very, very clear that if you look at the determinants for a longer life, one of the key determinants that overrides things like obesity and not getting exercise and stress and, and, and, and diet, smoking, you know, all these things that we're taught are really important for a longer life. Actually take a back seat. They're important, but they take a backseat to relationships. Social capital is absolutely critical.

Melani Dizon ([19:54](#)):

So, where does desire fit into that? So, I think like everything, there's going to be a spectrum and there's going to be the, the person who feels socially connected because they just have this giant group, right? And there are others that really like to be alone and could spend a week alone and have no problem. Is there any relationship there between the healthfulness of being socially connected and the desire to be like the, I my, my understanding is that the, the expectation, the desire is where the big gap and the pain is? But if you're, it's not really your thing, you're not going to have the negative side effects.

Dr. Al Condeluci ([20:37](#)):

They, you know, that's a, that's really, it's such a great, a great question now. And, and, and, you know, you can, you can take the question and Joe almost it from a phenomenon of introversion and extroversion. You know, there are some people who are, who are naturally shy. They just are introverted. They, they don't do well in social settings. Right? And then there are extroverts, you know, backslappers and people that are the, you know, hit or the party and, and most people fall somewhere in the middle there. But, but you know, if you take a bell curve and you sort of think about that, you know, there are some skewed extroverts, some skewed introvert, and then most of us that, you know, that at times can, can, can be lively. And other times we want our, our, our you know our, our privacy and, and, and our quiet time.

Dr. Al Condeluci ([21:36](#)):

But with social isolation, there will have been now some numbers that have been looked at that really are telling whether you're an introvert or an extrovert or somewhere in the middle. And, and that is conventional studies that have really looked at how many people does it take in your life to literally somehow some way guard against being socially isolated. And the, you know, the, the, the, the, the data is beginning to show that the cutoff point is five, five important friends. It could be, you know, partner could be a spouse, you family members, close friends, but five is a tipping point number. And that if, if a person has less than five really, you know, intimate connections. And when I mean intimate, I don't mean that from a, a sexual point. I, I really mean it from just a trust in a, in a really, you know, a deep connection with the person.

Dr. Al Condeluci ([22:44](#)):

And so, five seems to be this tipping point. Now the with somebody falls under five really close friends for whatever reason, either because they're shy, they move somewhere, they're there, they're feeling in that they're feeling like, you know, that people don't understand them or whatever might be the cause that that could put the person at risk of, of some of the ill effects of social isolation. Now that doesn't mean when you run out and make five friends and you're going, everything's going to be fine. But it does give at least a little bit of a sense of the differential between isolation and knowing isolation and, and, and so now when you talk numbers two, interestingly enough now, just to quickly add the some anthropologists and, and you know, social psychologists bet, look at social capital feel that the typical person has about 150 relationships in their life with social obligation.

Dr. Al Condeluci ([23:57](#)):

Now that's the, that's the key word, that you have some obligations socially to that person, but 150. Yes. That's a pretty robust number. And when you, when you think about it, I know that often if I'll say that in a presentation or write about that and people react to me say, Oh, what are you 150? I can't even think of, you know, five or six. But if you really sat down and did an inventory of your connections to people, and the best way to think about that is your connections vis-a-vis the social platforms that you that you play in or that you are involved in. And what I mean by social platforms is like your family is one platform. If you work that's another platform, your, your coworkers, a church going, that's another platform, a neighborhood that's a third, you know, a fourth, fifth platform, clubs, groups or associations that you belong to.

Dr. Al Condeluci ([24:56](#)):

Even things like Facebook. Exactly. The, so the virtual social capital you know, frameworks, but, but 150 is really one what some of the anthropologists really think, gives us sort of a, a kind of a number to shoot that as it relates to social obligation. And, and they even tie in that, does he really feel that, that people that our limbic system, you know, our brain and our, our brainstem and, and our primitive system can really only manage about 150 friends that, that when you look back at tribes or, or villages the average number was about 150 in a, you know, in a tribe and that you just weren't able to really process that more than that. No, no. In today's day and age obviously that, that, you know, that number is, is changed and we really push our limbic system. But those are the numbers. And when you talk about desire, you know, that those really important people, five now the average by the way of those really important people is about 18, right? 18 is about the average number of these really close relationships. The, that are intimate, trusting relationships. But five is like the tipping point.

Melani Dizon ([26:28](#)):

[Inaudible] And there was an, I wish I had brought it, a recent study. There were somebody talking about that there was a pretty big percentage of people that didn't even have that. That's tough. When you said 150. I let her, my whole body just got heavy and I was like, oh my God, that sounds exhausting. But so, what, what is, we talked a little bit about it, but what's the biology of social isolation? And then once we get through that, I want to talk about some of the you know, what's going on now and the things that you're doing with people in your community and things we're doing. But let's talk a little bit about the biology of social.

Dr. Al Condeluci ([27:10](#)):

Just really quickly. This is really fascinating, Mel, that again in, in, in a little bit of a deeper dive in looking at social isolation and loneliness [inaudible] there has really now been some very, very strong evidence that when someone is rendered isolated that the biological flow changes for that person. Let me give an example. Back in our primitive days when we were hunters and gatherers, you know, and if you were with the tribe, you were safe and your system, you know, would function, you know, normally. But if you were separated from the tribe for whatever reason, got lost or somehow just got, got this attached. What begins, begins to happen biologically is respiration begins to increase circulatory stress begins to kick in the nervous system and gets very you know, very, you're, you're, you're alerts because of your precarious situation.

Dr. Al Condeluci ([28:28](#)):

If you were rendered to be isolated from your tribe, you're at risk of dying, right? So, all these systems begin to kick in and, and, and they help you. They're like defense mechanisms. They help the person get back to the tribe, get back to their social capital. Now, so that's a good thing. You know, that, that the biology kicks in, but over an extended period of time, it's a bad thing. Because if your circulatory system, if your, you know, your heart's racing and your blood pressure is going up because you're, you know, you're worried about you, your precarious situation, you can't wait to get back to the truck. That's over a long term that's really going to have some negative effects. And that's why researchers, medical research have really begun to look at social capital and its tie to health and, and, and you know, where right now today mill as we see day in and day on Americans and people all over the world dying alone in nursing homes from the sea because of the covert 19 a situation and the social distancing and, and, and, and the only solace is a, is an iPad with maybe a loved one that you're looking at, but no one to touch you at a whole Jew to embrace you.

Dr. Al Condeluci ([29:59](#)):

Those, that biology, that stress can even be more emphatic. And, and you know, and it does not surprising to me that we're seeing these, these, these, this just her read this number of deaths. But the, the, the, the thing that just rips your heart out is that these people are dying alone, right? They're, they're dying. The most isolated situation with these machines beeping. And so, the biology of social of social isolation is important to understand because your stress levels go up and if your stress levels stay up, they affected your immunity system, your strength, your health-related strength. So, it's important to know that we've got to get people to their tribes. We got to get people back to those kinds of connections. And that's really what I worry about with this pandemic now stay at home orders that we're all under is that, you know, some of us are fortunate enough to be with our husbands or wives or partners and, and our family.

Dr. Al Condeluci ([31:17](#)):

So even though we're, we have to stay at home, we have other people we can talk with and that we can engage. But for singles folks that are single or by themselves and they're stuck in an apartment or a home by themselves, this is really, really toxic stuff. And so, I think in terms of finding ways and means to get connected to stay connected. In fact, just today, I you know, I'd been preparing for a webinar and do later this month that's, that's designed for agencies that serve people with intellectual disabilities in group homes and in supported apartments. And, and, and the talk that I'm going to do with them is really about how can staff help keep people engaged in an era when we have to be distant. And so, you know, I'm, I'm looking for a whole variety of methods and ways and I found a website just today called house party.

Dr. Al Condeluci ([32:27](#)):

It's an app and you could download the app and if you have your close friends download the app as well, you can engage with them more than just like with a Skype or with FaceTime or with portal where you could see the person and you are having a conversation with them. That's nice. But with, with this house party, you actually can engage in some games and some activities together that that adds elements to the connectedness than just seeing, like, like, I'm sitting here and I'm looking at you now on this webinar and I can see you. And that's great. That's, that's

wonderful. That makes this interview so much more personal you know, for, for, for me. But just seeing a person is not enough. We've got to engage, we've got to participate with them and now doing that when we have to stay distant and we have, we can't go to gatherings and, and, and, you know, and we have to, you know, wear masks and that, that just continues to challenge us in finding ways that we can engage, that we can actually do things together.

Melani Dizon ([33:47](#)):

Right. Well, one of the, one of the things that's such a big concern for our people with Parkinson's is that many of them experienced anxiety before this happened. They just have a, you know, a, maybe a lower level of anxiety or something they're constantly sort of working with. And then when, when this happens, you know, that feeling of, yeah, I'm not with my tribe. I can't go to my exercise class that I go to every single week. And I see Tom, Jerry's, Sharon, Sharon and Sally, right? Like, I can't do those things. It, and I can't get toilet paper, or I can't go to the store when I need it. I mean, their anxiety just gets worse and worse and worse. And so there, it's this like physical response to that feeling, but then also they're physically not doing what they used to do to manage the anxiety.

Melani Dizon ([34:44](#)):

So, it's just like this double whammy. Some of the things that were, you know, that we've tried to do is, you know, obviously we do a lot online. We've one of the, we offer a sketching class once a week where people can come and talk to each other and, and sketch and we've said, okay, maybe if you have a, a workout class you can ask your instructor to bring it online. And so, all of you guys can do it together. Can you have a meet up with your exercise class that you do every day? Poly and Davis were poly was telling me yesterday that she and Davis got on the phone. I mean, yeah, got on the phone or they got on zoom and they just rode their bikes together. And so the, you know, the hour goes by really fast.

Melani Dizon ([35:33](#)):

None of those things are as great as being in person. But you know, a 32nd phone call can connect you to somebody and say, Hey, I'm just thinking about you and how are you doing? And, and is there anything I can do for you? And I think that it's there's not going to be this one big answer right now, unfortunately. But there are those little things that you can do every day. And one of the things that we suggest is do at least one thing a day and just do one thing to connect with people. Pick up the phone, you know, go outside. And you know, a lot of people are that are able to, are going outside and having like you know, two feet, six feet away party, right, where they're just far away from each other and talking and or go for a walk or whatever you can do.

Melani Dizon ([36:23](#)):

Somebody was saying that, you know, they have been in isolation for a really long time. This person is lucky. She's in an active retirement community, so she's still able to, my guess is that able to kind of connect with people in a certain way. But I would also love for people in the chat to say, what are some of the most helpful things that you've done over the course of the last month or two that have helped you stay connected with people? Because I think people want to hear it and they want to get all the ideas they can get, right?



Dr. Al Condeluci (36:59):

Yeah. Yeah. Your, you know, your points again, so well-taken Mel and, and the, the notion of, of, of engagement is at the core here, but there is some low hanging fruit. I mean, the example that you gave, just picking up the phone and calling somebody that requires a mindfulness. I think it's important that we need to remind ourselves that staying connected is critical and it's critical for me and it's critical for the person I'm reaching out to connect with. So, so they're in really lie the, I think the, the baseline, but the anxiety issue that you raised is, is really, it's real and, and it's powerful. And there may even be some throws that, that, that creep in because of a disability. I know with my dad there was some heightened anxiety to do things, but one of the things that mitigates anxiety or that can at least lessen it to a certain degree is if the point of contact is something that is relevant to you.

Dr. Al Condeluci (38:16):

Like, let me give an example with my dad. He was you know, a writer editor of the paper [inaudible] but he was also a musician and he tied together his musician skills with writing. And so became a reporter for a downbeat magazine where he would cover concerts, jazz gatherings in Pittsburgh, our hometown, and he would write about them. He'd write an article and he'd send it off to the downbeat. And sometimes they ran them, sometimes they didn't. But so jazz music was always, you know, for him, something he really, really loves. And, and so when his Parkinson's started to unfold and, and dad began to really, his anxiety started to go up his self-confidence and, you know, his, you know, his sense of other people basically, you know, looking at him or backing away from him, the, all these social cues that, that, that signal, you're not welcomed here or, or, or you're different from me, you're weird.

Dr. Al Condeluci (39:33):

Those would kick in. And that even heightened my dad's anxiety causing him to want to just cocoon, you know, just to stay, you know, in, in, in the yard or just saying house. And, and, and so one of the things that we, we used as a bridge of engagement for dad was, was his interest in music and his interest in jazz and, and, and what we did, the lesson, the anxiety was that, you know, we got dad involved with the Pittsburgh jazz society you know, a group here in our town of jazz affection, autos. My dad's experience with jazz and his opera, his, his, you know interviewing of, of dizzy Gillespie and an elephants, Gerald and Earl garner and all these great jazz people. My dad actually got to meet when people found that out about my dad, that it may, his relevance go up.

Dr. Al Condeluci (40:40):

And even though he didn't feel relevant physically what we wanted to do was raise his relevance. Yeah, topically, you know, and so he, you know, his, just his experience as a musician when, when he got involved with the, with the jazz society boy that was, you know, that so the other folks in the room and saying like, you mean you interviewed Stanley terantin, you knew it. You know, and so anxiety goes done when relevance goes up. And so if we think about, you know, if, if folks listening to the webinar can think a little bit about what is their bridge of relevance, and then now obviously in the throes of this pandemic, we've got to figure out, well, how can we do that virtually? Or how might we do that in a way where social distancing can be, you know, honored.

Dr. Al Condeluci ([41:41](#)):

But nonetheless, I think finding that bridge of relevance is really the first step in building social capital and in, in beginning to bring people into your life and, and finding new tribe members. The one thing I want to really stress with, with the audience with the folks that are, that are plugged in today is that we have all different tribes. You know, when I say you want to get back to your truck I, I, I want people to understand that your tribe is not just people with Parkinson's, right? That, that, that is one of your tribes. You know, just like Italians, you know, there's one of my jobs, but, but you also have tribe members in the other things that you like to do or that you have some competence in other, you know, if it's cooking, it might be wine, it might be, you know, music, it might be bike riding whatever your, you know, relevance.

Dr. Al Condeluci ([42:48](#)):

That's your tribe. That's another one of your tribes. So, getting back to the tribe is really not a, that's not, I don't want that to be songs as well. I got to be with my Parkinson's tribe. Being with the Parkinson's tribe is fine, but there's all kinds of other tribes. And, and when you venture into these other tribes two really good things happen. One is you begin to feel like you're multidimensional. You're not just this, this Parkinson's person. But the other thing is that the other people in the tribe who do not have a disability and maybe have no knowledge of Parkinson's, they learn a little bit here. They, they broaden their awareness, right? So, it has, it has two positive outcomes. So, I think finding your tribe, thinking about what is it that I really am good at, that I like to do, that I care about, that I'm interested in.

Dr. Al Condeluci ([43:51](#)):

What is my passion, what is my advocacy? And then finding your way across that bridge to that tribe. Now, obviously today we have to think about that from a virtual perspective, but that's not going to be forever. I mean, we're going to, we're going to get by this hopefully assumed, but, but this will get, this will pass. We may know some of the norms of society will change, no question, but finding your tribe and then knowing that you have an interest just like everybody else in that particular topic, mix your relevance. Go

Melani Dizon ([44:32](#)):

Up. Hopefully should make your anxiety go down. Yeah. One of the things that is that's very evident in our moments of victory stories that people share is the, the theme common theme over and over again is they took something they may have been a little interested in before and now that they have Parkinson's, they had a renewed interest in it and now they're sharing it with everybody else. And you know, somebody was a personal trainer and now they're a rock steady boxing coach and they're working with all those people, but they're, they're still working with their other clients and, and it's, Oh, the, the ones that seem to be living well with it the best are those who have found that piece. Before I ask another question, I wanted to go through and share some of the, the ideas that people have shared about what they've been doing.

Melani Dizon ([45:22](#)):

So, some people said FaceTime with family. Yes. somebody said please don't suggest two feet. Yeah, that was a mistake on my part. I said two feet. I really meant six feet if not more. We've been zooming with family and old friends as well as our Parkinson's group. Yes. Calling family

members. Mostly we connect through text messaging. Somebody said a Jenner Jenny and said we've played dice games over messenger, trivial pursuit over FaceTime and categories over zoom. Excellent. Yeah, that's, that's so good. My family and I had a, we had two birthdays this week and then Easter, so we had we just all sat at our dinner tables and had Easter dinner together. Over zoom. Let's see. My organization is offering training and assistance to our support group facilitators to move their groups online conferencing apps or to conference calls whenever possible.

Melani Dizon ([46:14](#)):

That is great. We've added additionally expanded our online exercise recreation enrichment program offerings. We realized that online solutions are not a panacea, but it is a move in the right direction while we are considering additional options. Absolutely. That is, I mean, we can do what we can do right now with the information that we have. And I am really so impressed and so excited that we have so many things to share with the Parkinson's community because this group, I don't know if it's everywhere, I'm not in every other community, but I'll tell you when this was, when people got locked down, the Parkinson's community responded and everybody's online and really trying to help and I love it. Let's see. Book club meetings on zoom. Yup. Helps with connections. Definitely. That's so good. Two prayer groups online. Gosh, this is great. Let's see.

Melani Dizon ([47:05](#)):

Somebody said it's hard when a person with Parkinson's is losing the capacity to cook. It sounds like supporting the person to participate in these activities or having him observe and give tips while you cook. Sadly, this is not possible when you're not able to visit care centers right now. Absolutely. That's really tough. That's really tough. But I love the idea of letting the person kind of share ideas even if they're, if they're not able to with their hands or mobility. Somebody said, what do you suggest when a person with Parkinson's is good at chess and bridge, and yet his capacity to be alert for the period of time required to play the game is not there. It says game flag. I think I'm misreading that, but what in general I would, I would think get with people who are willing to place a hold on games.

Melani Dizon ([47:50](#)):

That happens all the time. Just put a pause on it and you can do that over zoom right now. You can say, great, I'm going to play this, and you know what? I don't have it right now. Let's put the game down. I trust you. Put your cards there, we'll come back. Here's the chessboard, we'll come back. I think that's a great, yeah, a great thing to do. Let me just see if there's any other questions. Let's doing it. All those types of things. Writing my husband used to be a prolific writer since Perkins. He doesn't do it at all. I've been pushing him to journal just for him. He is doing it, although typing is slow. Yeah, that's tough. It connects him somehow to himself and let some see that he's still has such insightful things to say.

Melani Dizon ([48:29](#)):

I think that is super important and what a great activity to do and I'm hoping he will share with trusted people eventually. That's really great. Let's see. Connect via zoom with families, rock steady and YouTube for many things, music, concerts, church, et cetera. That's the, I mean it's

amazing, right? We have everything about like I'm learning her for now. Isolated seniors, not computer nor smart, phone savvy. Love how instruction set up. Trying to help even older generation with hearing problems too. And computer overload connect. Thanks for all you do. Yes. one thing I would recommend if you do have somebody who has hearing issues and this kind of thing is really difficult where whoever you're working with ask them, Hey, can you do a transcript of this? Like there are so many amazing services right now. You can get a transcript in 30 minutes. It's not a perfect transcript, but it's really totally sufficient. So, most people can do that. How do you play cards online? Well you, so you could play with a friend, right? You could just say, here's, and we're going to play in here. I'm throwing this down. But they're all lost lots of online card games. So, you could do that for sure.

Melani Dizon ([49:39](#)):

Oh his, I can't recall now the side, but there's living history project where you can tape record interviews and with older people about their lives. So, I think the one you're talking about, I'm not sure is the legacy project.org. It's amazing. I actually did a memoir with my dad through letters using some of those questions and some of their materials. Really interesting. So, Andrew Lloyd Webber free played on YouTube every weekend. That's amazing. Yeah. Wow. So that's a lot. What, what else do we need to talk about out?

Dr. Al Condeluci ([50:12](#)):

Yeah, well you know, just to add, you know, adding a little bit to the list that you, that you just reviewed that, that folks that just these robust ideas, but you know, now museums and or an art museums are doing tours. Some of the great art museums in the world. You can, you can actually do a virtual tour and you can do it with other people. So you can you know, be going through the art you know, a gallery and looking at the same the same image and, you know, reacting with your, you know, fellow art affection ADOS as to what you see or how the, how the, the painting speaks to you. So, these kinds of virtual things are really out there and there's more and more being developed every day. I mean, that's, that's one of the things about this pandemic and stay at home orders, is that it really is bringing on these, these brilliant ideas that people who are coming up with and ways and means to stay connected, to have a chance to express yourself, to, to really be with other people who share your passion, whatever that might be.

Dr. Al Condeluci ([51:37](#)):

So, so those, those are just some wonderful ideas. And just a quick postscript on that is I'm involved in a project right now as we speak with this organization called [inaudible]. It's a, it's a trade association that, that the American network on community options and resources is what Amcor stands for. A NCOR. And we just, we, I just did a video for them that we released that is getting people to do exactly what you just did mil. And that is to do some group think and to come up with some ideas strategies ways and means. And so we put on a survey monkey through Amcor to all their members and, and on April 27, which is a Monday at one o'clock Eastern standard time, we're doing a free webinar where we're sharing these ideas that we gathered through this sort of virtual survey monkey conversation with people from really around the world.

Dr. Al Condeluci ([52:53](#)):

And core members are actually from around the world. And we're going to be summarizing these in a one-hour webinar at one o'clock on the 27th of April Eastern time. We're going to follow that up with a white paper that, that basically, you know, writes down these ideas and I'll make sure Mel, that I get that paper to you. He doesn't be a public document. This is not proprietary. It's really designed to just give people ideas you of things that they can do to stay connected, to be connected, to build social capital and maintain social capital. So, I'll, I'll get that to you and maybe we can share that on the Davis Phinney website.

Melani Dizon ([53:37](#)):

Yeah, absolutely. And we'll, we'll share the webinar to when we get this. Yeah, we'll share that. The, the thing that I think is going to come out of this one, one of the great silver linings is that the amount of content that is being digitized and is now in library. When people go back and people are able to connect with their people and to be able to go to their classes, they're going to be times when they can't. And now they don't have to miss anything. All of these things are going to be available to you. So, it's, it's going to be a time where we look back and be like, wow, we still have all of these things that we can do. Even if I can't leave the house for whatever reason the, somebody has asked about studies on social, social isolation and Parkinson's and there are about social isolation and health. I will be sure to share those when I share the show notes for this. I will share the, those studies. I will share the Ang core talk that you just said, the webinar. And I'll also add that

Dr. Al Condeluci ([54:40](#)):

That'd be great. One thing that's just add to this is there's been obviously prior to this pandemic there were, there was a lot of interest in social isolation and loneliness and, and there was a study that was conducted in 2018 published in 2019 by Cigna insurance company, Cigna CIG DNA. And if you Google Cigna loneliness study, Cigna loneliness study, you just Google that in. The report comes up and this was a, this was a study male that was conducted throughout the United States with 20,000 individuals. Not, not people with disabilities, but just generic individuals around America and various regions of our state, various ages and experience levels. And they use the UCLA loneliness scale. Now UCLA back in 1968, 69 created this loneliness scale that actually measures loneliness. And that's by the way, also on the web, you can, you can just Google UCLA loneliness study or UCLA loneliness scale.

Dr. Al Condeluci ([56:01](#)):

And, and it comes up, there's 20 items and it's, it's a, it's a it creates a score. So, when Cigna did this study using the UCLA loneliness scale, 20 items, 20 questions in the survey they discovered that the loneliness benchmark had in the United States, but almost 10 points. Now the scale is 20 to 80, 80 being you know, really lonely, 20 being very connected. And this the average in the United States was about 34. And then when, when Cigna did it, it's gone up to about 45 points. And so folks, if they're interested in digging a little deeper on social isolation, loneliness, they can take a look at this sickness study, look at the results from the sickness study and also maybe Google the UCLA loneliness scale and have a chance to sort of look at it, maybe even take it. You can actually take the scale and get a sense of that to get a better understanding of loneliness and isolation.

Melani Dizon ([57:18](#)):

Yeah. Well this has been great. It's been, so I wish we had more hours to chat for everybody on the webinar. We will have this recording available to you soon and you'll be able to listen to it indefinitely. As long as we're around this video, we'll be around. If you have any questions at all about this topic, please email them to [me@mdizonatdpf.org](mailto:me@mdizonatdpf.org). And if I can't answer it, then I will reach out to Al and hopefully he can answer it. And yeah. So, thank you all so much for being here. Al. Is there any, any final words that you'd like to share?

Dr. Al Condeluci ([57:58](#)):

Yeah, just wanted the folks to [inaudible] again, if you're interested in more in social capital, take a look at my website, which is just my name, Al [inaudible] dot com. And my Ted talk is on there. I did a Ted talk a couple of years ago on social capital and, and some other materials, some uploaded materials that you can take a look at to learn more about social capital more from a sense of how we build it. So, Mel, this is really just been for me an incredible delight. I, I'm such a fan of the Davis Phinney foundation and the work that, that that you and your associates are doing in terms of living well with Parkinson's. I got to learn about the Davis Phinney foundation and through my experience with the Parkinson's foundation of Western Pennsylvania and my dear friend David Vaughan orphan, who I think is on this webinar, and he introduced me to Davis. So, I had a, you know, it's really kind of full circle for me. So, I appreciate all the work you guys are doing.

Melani Dizon ([58:59](#)):

Great. Thanks everybody and thanks Al. See you guys soon.