

Lucas: Welcome to Bridge the Gap Podcast, the senior living podcast with Josh and Lucas. A great episode on today around the topic of dementia. We want to welcome Dr. Cameron Camp to the program. Welcome to the show.

Dr. Camp: It's a pleasure to be here. Thanks for the invite

Lucas: Dr. Camp, you're a psychologist. You're also the Director of Research and Development at and the founder of the Center for Applied Research in Dementia. You're an author. You have a book called "Hiding the Stranger in the Mirror." You're out of Ohio and you do work with people all over the world related to dementia. And so today's topic, we're going to be picking your brain, so to speak, around these groundbreaking new ideas and research that you guys have are involved in. Talk to us about this idea of a Montessori approach for dementia.

Dr. Camp: So Maria Montessori was the first woman physician in Italy, turn of the 20th century. And she was working with children in the poorest part of Rome, the San Lorenzo District, preschool children. They were destroying property and the tenements left alone during the day. So she was a physician pediatrician, and she was asked by the owners of the tenements to do something about these children, to give them something to calm them down, which is very similar to the phone calls that physicians get from nursing homes when dealing with challenging behaviors or what we call responsive behaviors in people with dementia. And she said, I'll help you, but you have to give me something. You have to give me a room to observe the children and someone to train, to work with them. So she was given a room, a desk, a chair, a table. The janitor's daughter, and that was the first Montessori school.

So when people tell me there's no resources available. I always think back to what she started with, but what she understood was you have to work with the capacities that a person has. You have to build on that. And you also have to be able to give people a reason for living. You have to give them respect dignity. You have to treat them with equality. You have to develop trust. So what she did was she developed an educational system for these children that were based on very basic human values. You know, when I'm in France, I always say, I see these three words on your flag, on your buildings. (inaudible) Why should a citizen lose these because of a diagnosis? And so everything is based on these values. And she was also a specialist in rehabilitative medicine.

And so she said, you know, trying to teach children by having them all sit still in a classroom and hear the same thing and be treated the same way is crazy. We need to give people freedom. We need to enable them to follow their own path. We need to create the environment that will enable them to be as independent as possible. You know what she said was everything you do for me, you take away from me and that's what guides all of our work with persons with dementia. You can do everything. For example, if you're a parent for a child, try to keep them out of danger, make sure they never fail. And it doesn't end well. We've all seen that. And that's the hardest part of parenting is to watch. And to know that you can't do everything for the person, but this is how independence is developed.

And in a similar way, when we do our work with dementia care, we followed that same path that Maria Montessori laid out. We remember another one of her quotes. "We do our job best when they do not know we are present." So in long-term care, for example, we encourage the development of resident committees, people with dementia, who decide where they want to go for outings, who decide what they want to do for activities, who decide what social causes they want to support. We have community in Largo, Florida, that's worked with us and they had a social concerns committee and one of their memory care resident's neighborhoods. And they picked a commute cause every quarter, one quarter it was hunger. So these persons with dementia, were setting up a food drive and gathering the food for their outing, they took it to a church that was a distribution center. Then they decided to create toilet packets for the homeless and for their outing, they took these to a homeless center.

That's a very different approach to dementia care. It's about enabling people to have a reason to wake up in the morning, to have purposeful activity, to be treated as a normal person. You know, we say that a person with dementia is a normal person who has memory deficits. That's important. It means that you begin to look at dementia as a disability, rather than a disease. It changes everything. Our duty for people with disabilities is to create environments that enable them to circumvent their deficits. We put in ramps so that people with motor disabilities can get into a building independently. Where are the cognitive ramps in our society? Where is the effort at inclusion for persons with dementia? So when we turn that corner, when we begin to think of dementia as a disability, it changes our whole perspective.

Josh, I see that you're wearing glasses. Yes?

Josh: Yes I am.

Dr. Camp: So if you took off your glasses, would you be able to see very well?

Josh: You would be just a blur on my screen.

Dr. Camp: I'm going to do a little exercise here, Josh, if you don't mind, would you please take off your glasses?

Josh: Oh, I'm the experiment. Here we go, Lucas. I knew this was going to happen. Here we go.

Dr. Camp: You knew it was dangerous. Josh, I have something to tell you, you have Cameron's Disease. It affects the vision. They'll get worse as you get older. We don't really have a cure for it. I have some medications I can give you. They don't work, but they are expensive. And they do have side effects. I'm going to give you a card, it's for your caregiver, because see, you can't drive a car with your vision like this. And your caregiver can join a group of caregivers who also are taking care of people with Cameron's Disease. So they can talk about how hard it is. You can also join a group of people with Cameron's Disease to talk about what you can't do anymore. Come back in six months. We'll see you.

That is the current approach to treating Alzheimer's disease. If you treat it as a disease, now I'd like you to think about this: Josh, you have Cameron's Disease. We're not going to call it that. You've got some

vision problems, but we have a way of helping you get around your vision problems is a thing called glasses. Why don't you put these glasses on? How's your vision now?

Josh: Oh, you and Lucas are beautiful men. So yeah.

Dr. Camp: Well apparently the glasses aren't working as well as I hoped.

This is the difference. So let me give you another example. My mother-in-law came to stay with us one summer and she was brought by her son by my sister's brother, who was doing an internship at the Cleveland clinic for the summer. And my mother-in-law had Alzheimer's disease. So they're staying at our house and he goes to the clinic and 20 minutes later, her mother goes to my wife and says, where's my son? And my wife says, he's at the Cleveland Clinic. He'll be back at 5:30. And that was the answer that made sense to her. But because she had Alzheimer's disease, she could not remember what my wife said after five or six minutes, but the need to know where her son was, was still there. So she comes back to my wife, because the information sheets can drop out of the woman's memory. She said, so where's my son? This is a prototypical challenge for caregivers, repetitive questioning. And we know what causes it. The inability to retain new information, typical approach is just be patient. Try to distract them. If you have to say the answer a hundred times a day, remember it's the disease. Have a nice day.

That's like me telling Josh, it's nothing much we can do about your vision. My wife being a Montessori teacher and working with me of course said, let's write down the answer to this question. So she writes down the answer in big letters. Your son is at the Cleveland Clinic. He'll be back at 5:30. She made sure that the mother could read it. Ideally you want the person with dementia to write their own message in their own handwriting because they'll trust their handwriting, not yours. And you want to make sure that it's the right message. How do we know if it satisfies them? If it answers their need. And then she said, let's put it here.

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She tapes it on the kitchen counter. Because if you don't tape it down, you'll be taken up and put into a place that's safe that no one can remember where it is. We know how to make all the mistakes, we've learned from that. I welcome my mistakes. And so 10 minutes later, her mom comes to my wife, asked the question and my wife says, you know, there's a message about that. Let's go see. And she takes her mom to this location because persons with dementia can still learn. I mean, that's like the great secret that no one talks about. You know, we expect them and they do. They learn where they're going to sit. You know, if they go to a day center, they learn where to sit. If they're in long-term care communities and they do it automatically unconsciously effortlessly, this is the same learning system that shows up early in life and that Montessori used to as an educational basis. Learn by doing it's called procedural learning. You learn by practicing procedures. So she goes to this location instead of reading it for her mom, my wife says, what does this say? The mom reads the message. It's the content that satisfies her. And my wife says, that's right. Whenever you want to know about where your son is, we'll come here. 20 minutes later. Where's my son? Same procedure. You know, there's a message about that. Let's go see, goes, looks, reads. Her anxiety's reduced. 30 minutes later, where's my son, same procedure. And for the rest of the day, when her mother's anxiety would rise, her mom would take herself to this location, read the message. It's the right message. It reduces her anxiety. The reduction of anxiety becomes associated with this procedure. And with this location and my wife enabled her mother to reduce her own anxiety, which also frees the mother then not to be carrying that around all the time and to be able to do other

things, to be engaged and not to be constantly worrying about where her son is. Simple, straightforward, anyone can do it.

So why haven't we seen this as a public service announcement? Why haven't we seen this as a cognitive ramp offered to the millions of people who are trying to take care of persons at home and under incredible stress by repetitive questioning among lots of other responsive behaviors? We call them responsive behaviors. We say they're a form of communication or response to an unmet human need. As from US Cohen Mansfield's work. Why don't we have this being pumped out into the world instead of a medication that costs \$32,000 a year of questionable value with side-effects.

It's time for a revolution in our way of thinking. I'm frankly tired, tired of listening to the same approach over and over again. How many failures does it take until we say, there has to be a different way. And so this is what we're about. We teach people how to use the capacities that persons with dementia have to enable them to circumvent their deficits, to enable them to be able to find their own ways within a community to be able to help others.

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We're about to start a project in the very near future where we'll have persons with dementia performing puppet theater for young children. Think about it, what abilities do they have? So they can read the script, you know, hand puppet. If a person can't talk, it doesn't matter. There are plenty of non-speaking parts. There's also parts for creating the scenery, for writing the scripts, for prop master. And you don't have to explain to any person with or without dementia the importance of working with children, the joy of entertaining them. What's keeping this sort of thing from happening as the standard approach to how we deal with dementia? And the answer is old ideas. Old ideas. So this has to change. We have to start with a fundamentally different approach to how we think about what dementia is and how we work with persons with dementia.

We have to give persons with dementia, the capacity to live well with dementia like people live well with diabetes. Like they live well with cancer. It's about creating a better quality of life. It's about normalizing having dementia. I'm not saying that dementia is an easy thing. I'm not saying it's not a bad thing. But what I am saying is that if we treat it as the disease that is viewed as untreatable, has no cure for, and all we can do is sit around and wait for the magic bullet. That's crazy. And it's unnecessary. And so this is what we're about. We do research to demonstrate what these persons with dementia are capable of doing. And then we kind of like put it in people's face and say, why not? Why not make this the standard? I mean, our goal is to change the standard of dementia care in communities that are residential and day centers and in homes.

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It's interesting, sometimes when we show these things, people get angry at us and they say, are you saying that, that we messed up, that, that we did things badly all this time that we've been providing care? The answer is no, you've done a great job. You gave your heart, your soul. You took on the toughest job there is on the planet, and you did the best you could with the information that was made available to you. We've been fortunate to encounter a different set of information, a different approach that we want to share with you now. And that's the God's truth. Okay? That is the truth. And that is the message that we have to get out there. There's a better way. And it's being done in places around the

world.

I was talking before we went on about a woman in Northern Territories of Australia, Aboriginal woman who came into a nursing home, very different from her standard culture where she was living. So the staff brought her in for a shower and she flipped out and she got hysterical. And so a nurse went back to this woman's village and did some observations. And the next day, when they wanted to give her a shower, the nurse took her outside, found the flat rock, got some screens to put around the rock, to give privacy and gave her a garden hose. And the woman took off her clothes and washed herself. And this is how women in that village clean themselves. Now imagine someone from that culture being dragged into a rock cave, shower stall, suddenly hot water squirts out, and you've got people holding you down, forcing you to stay in that stream of water. What would you do? So this is the point we say, it's a human thing. We have to see the person in person with dementia.

We have to realize that these people are acting the same way you and I would under exactly the same circumstances. You know, we have the video on our website. And the video is called Alzheimer's Syndrome in down's disease. And we asked this question, what would it be like if we treated Alzheimer's disease and dementia in general, the way we treat down syndrome as a society? Where's the Special Olympics. Where's the person with dementia who has a recurring role on a TV show? Where is the poster at LaGuardia Airport, like you see with the person with down syndrome and an athlete, My buddy? Where's the real push for inclusion and visibility for persons with dementia. Now, what if we treated people with downs syndrome as if they had downs disease? Why have we treated them the way we treat people with Alzheimer's disease?

I think I have a clear vision. It'd be like turning the clock back 50, 60 years. Cause that's what it was like people were shut aside, not included, viewed as something that you didn't want people to see. We have to change as a society, our set of values.

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Lucas: Dr. Camp, this change that you're talking about. I know that you've received both a welcome reception to this, and then also probably a lot of questions. And it is a very revolutionary topic. You know, Josh, you have been involved in raising money for Alzheimer's research with you know, [Pedal for Alzheimer's](#). And this is something that we've talked about multiple times on our episode is such an important topic. And Dr. Camp is on covering a lot of really actually common sense approaches, but for whatever reason doesn't seem that common.

Josh: Well, you know, it's really interesting because I was, I was listening to you, Dr. Camp and going back, and just my limited 17 years of experience of caring for older people with no medical background, no healthcare background really coming into this just learning. As I think back I was, we were opening our first memory care and I remember thinking, well this doesn't make a lot of sense, but this is how I was taught to do it. Everybody needs to get up at this time. Everybody needs to eat at this time. This is the shower schedule. Everybody does it like this. I was instructed that these medications, this schedule, this is the way you do it. And it wasn't until I saw oftentimes it not working very well that I started to question, but I can tell you, as I started to get a little bit more exposed and started asking questions, I was just sharing with my team. We're about to open an assisted living community right now. And I was

sharing with them. Some of the things that I think what you're saying are formulating it, but just through common sense we've learned, but even our program that we developed years ago and in a community called Art from the Heart and people told me, oh, you can't do that with memory care. They can't learn how to do art and then we saw it flourish. And we saw these behaviors that we thought were somewhat bizarre, start to decline in the community. We saw the enjoyment. And the thing that I learned, and I took away from that without like science telling me that it was this way, or it should be this way, is that, you know what, regardless of what anyone told me, I witnessed people with Alzheimer's, different forms of dementia, learning to do things they had never done before, and also feeling a sense of purpose in doing that.

And so I really appreciate the conversation that you've had. I think our industry senior living as we call it is actually right for this. And we're starting to see a lot of positivity and a lot of change come and so I appreciate your efforts. And I know oftentimes whenever you're the new thought process or you're challenging something that has always existed in the same way. It can also be received with negativity, but we'd very much appreciate your work. It's been a learning experience. I feel like Lucas, our audience probably just got a half of an hour CEU credit.

Lucas: I mean, Dr. Camp, this is a topic we'd love to have you back on to discuss even further some more questions about where is this being used, how is it being used? How can people get research? We have limited time today, but would you be willing to come back on and, and further discussion?

Dr. Camp: I would love to, and just as a sort of a priming thing, we're also using this approach on how to engage staff. How to use the same approaches to enable staff to have more autonomy, to create community among themselves to be sustainable and not lots of turnover. So it's a system-wide approach that we're applying to dementia care in general.

Lucas: That's really fascinating that even just that correlation, I think deep down inside we desire that autonomy. A lot of times that's muffled by fear, right? It's a big tactic that's used to suppress people from really seeking that autonomy and that freedom that they need. So a lot of different ways to talk about this and very interesting conversation. Dr. Camp, we appreciate your time today. We are going to link all of your information in the show notes here and to all of our listeners, make sure that you go to [BTGvoice.com](https://BTGvoice.com) to download the transcript of this episode, connect on social, watch the video, or listen to the audio on iTunes, Spotify, or whatever you listen to podcasts on. Thank you, Dr. Camp for your time today.

Dr. Camp: It was a joy. Thank you.

Lucas: And thanks to all of our listeners for listening to another great episode of Bridge the Gap.

Dr. Camp: Sorry for surprising you Josh, but it always works better if it's not rehearsed.

Josh: Oh, that was wonderful. And you know, I like surprises and I can roll with just about anything it's okay.

Dr. Camp: I learned that example from the head trainer and head of research who our training partner organization in France, Jerome Marijke. So I always give him credit for that, but it really sort of illustrates the different perspectives on how you approach things. And so I always liked to use it when I can.

Josh: Well, and you know, I didn't mention this, but when you made me take my glasses off and you were telling me, you know, about these medications and this cost. And, you know, I found myself feeling hopeless, frustrated, and just my shoulders sagging like, well, what's the point, you know? And it's amazing just the different approach. And it's the, it's the same problem, right? It's the same problem. But even, even the way it made me feel as an individual was I went from hopeless to hopeful and your whole outlook, I would imagine, and a patient's outlook changes just on how you're communicating with them. So it's fascinating.