



# National Center on Advancing Person-Centered Practices and Systems

## Transcript:

### **“Person-Centered Supports for People with Dementia Living in the Community”**

*This webinar was originally broadcast on November 30, 2020*

\*Please note that the time stamp does not align with the recording.

10:00:16 >>ALIXE: Hello everyone, and welcome to today's webinar person centered supports for people living with dementia in the community

10:00:22 we are excited to have as many people as we have as we are having people join us

10:00:41 we will stay on this introduction slide for about one minute as people join and again we are tremendously appreciative for all of you that are taking time out of this Monday, November 30

10:00:45 to take part in this conversation.

10:00:48 With that, go to next slide please.

10:01:01 My name is Alixe Bonardi I am one of the codirectors [Reading PowerPoint]

10:01:08 I am joined by my colleague Bevan Croft

10:01:23 And we are delighted to be able to present this webinar series, which is sponsored as part of the national Center for advanced things

10:01:31 which is funded by the administration for community living and the centers for Medicare and Medicaid services.

10:01:39 All these webinars are free and open to the public, they are recorded and are available on our website as you will see

10:01:43 in later slides,

10:01:57 The goal is to promote systems change that makes persons centered principles

10:01:59 [Reading PowerPoint]

10:02:14 this is something that we have worked for in a number of different ways through our center, and one of the ways is through these webinars that are available publicly.

10:02:21 Thank you.

10:02:28 Just a few quick webinar logistics, all participants are muted during the webinar.

10:02:38 You can use the chat feature and zoom to post questions and communicate with the hosts, please note that when you are posting

10:02:48 you should post for questions towards all panelists and attendees because you want everyone to see your comments and questions.

10:02:57 We leave the chat feature open and we are delighted in many cases, there are rate great conversations and resources to share.

10:03:07 Towards the end of the webinar our speakers will have the opportunity to respond to any of the questions so go ahead and do that in the chat box.

10:03:13 This meeting is being captioned in both English and Spanish.

10:03:26 The English can be accessed by clicking the captioning but at the bottom of your zoom window.

10:03:34 Four Spanish can click the link on your screen or click the link that will be in the chat.

10:03:39 Please be prepared to interact as we move through the session.

10:03:52 The webinar recording as I mentioned along with a PDF version of the slides, and a plain language summary of the conversation will be available



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10:04:00 on the [NCAPPS.acl.gov](https://www.ncapps.acl.gov)

10:04:21 after the webinar you can send follow-up questions and feedback about the webinar to the email address, [napps@hsri.org](mailto:napps@hsri.org)

10:04:29 but please note that this email is not monitored during webinar so if you have any questions you want answered now direct them into the chat.

10:04:40 For everyone participating we want to know who's here, there is a pole coming up on your slider screen right now and we ask that people select

10:04:52 how you self identify, this is helpful for us and our team to know who's participating but also for our panelists to know who they are, and who they're speaking to.

10:05:01 It looks like we have over 500 participants in this webinar and it's a large group of people that is joining us that we are so appreciative of this.

10:05:05 It's great to know how people self identify.

10:05:17 Give people another couple of seconds and then close the pole and we can share the results.

10:05:44 So have nearly half of the people participating would identify as social worker counselor or care manager, this is helpful and showing that that's a great presentation for this group.

10:05:56 We are also excited that we have people that use long-term support systems, people with disabilities joining us as well as family members and self advocates.

10:06:07 As well as a large number of people who identify as government employees, and people from provider organizations.

10:06:13 This is a great spread of people who are participating and we're excited that you are aware this.

10:06:24 We are joined today by a terrific group of panelists.

10:06:33 Each person will be introduced and have more of an opportunity to speak about themselves socially, I just want everyone to know along

10:06:49 we also have panelists Brian Van Buren, Cameron Camp, Elias Rodriguez, and Rev. Cynthia Holling Hummel

10:06:55 before we get to the conversation there is a little bit of the laying the groundwork that I'm going to go through

10:07:01 in this presentation we are going to spend a little bit of time talking about definitions

10:07:06 four person centered thinking planning and practice

10:07:08 [Reading PowerPoint]

10:07:18 importantly we're going to hear from and share experience of supports [Reading PowerPoint]

10:07:28 and as part of that we will be discussing strategies [Reading PowerPoint]

10:07:33 we are really exciting to hear from

10:07:46 a national Center for advancing person centered practices puts forward these

10:07:48 [Reading PowerPoint]

10:08:02 person centered thinking is a approach that we suggest as a foundational principle which requires consistency in language values, and actions to place the person

10:08:13 at the center. The person and their loved ones are experts of the people in their lives.

10:08:20 They should be able to make decisions about how people want to live their lives.



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10:08:28 Person centered planning is a methodology as we define it that involves [Reading PowerPoint]

10:08:39 Andy supports both paid and unpaid the people would like to be able to achieve their desired life.

10:08:53 Person centered planning the process itself is directed by the person and supported by others that is chosen by the person who is engaged in the planning effort.

10:09:10 And then all this comes together in the context of person centered practices, this is where the alignment of services and systems come together to make sure that the person is has access to full benefits of community living.

10:09:17 Service delivery that release facilitates the person's desired outcome.

10:09:24 So all of these things need to be in place to really achieve a person centered system.

10:09:48 when we ask people what, they tell us what isn't person centered.

10:09:54 This is why we went to, wanted to present to you a little bit of this content.

10:10:02 With the systems focus the limits of the person has is what is used to define the person.

10:10:13 Supports are defined as services, people can become eligible for depending on the extent of their impairment.

10:10:27 This is the kind of language one can see in a systems focused systems, that is really all about meeting the needs of the system over more importantly perhaps

10:10:31 over the people that are receiving the support.

10:10:43 The supports are driven by the needs of the system. In a person centered approach, and this is the direction we want support systems to move towards.

10:10:51 A person brings their own unique capabilities and contributions, with strengths and preferences.

10:10:58 Also recognize that there may be challenges in planning for a future life.

10:11:07 So what that means is that there may be supports needed to help with the planning process and think through what is important.

10:11:14 It also depends on the capacity of the person and who they are, here's an example

10:11:25 when you think about some people who may be very naturally gregarious, very interested in being a part of a large group of people,

10:11:39 if someone needs support it may be that the support they need comes more from their community and their circle of support, they really choose have people call them and give them reminders perhaps

10:11:50 there might be other people who really are less interested in having that kind of routine connection around that kind of thing

10:12:00 and they may be more interested in for example having technology given them reminders, or technological supports for other things

10:12:07 this is where person centered supports can really meet the needs of the person depending on who they are.

10:12:19 We have a person centered advisory within NCAPPS

10:12:24 Kimberly Mills, her quote is beautiful and it says [Reading PowerPoint]

10:12:58 and that is the foundation that I want to leave you with.

10:13:11 Very briefly the overview of the unites states population



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10:13:23 According to most recent report, 5.8 million Americans of all ages are living with some form of Alzheimer's dementia in 2019.

10:13:30 This includes approximately 200,000 people under the age of 65 who have younger onset all timers disease.

10:13:36 Different causes of dimension are associated [Reading PowerPoint]

10:13:52 And this is sometimes person centered care as well.

10:14:04 I also want to point out that dementia and Alzheimer's disease are not experienced equally across among

10:14:15 people 65 years and older African-Americans have the highest rate followed by Hispanics followed by non-Hispanic whites at 10%

10:14:25 American natives and Alaska natives are 9%, and Asian Pacific island is 8.4%

10:14:35 and importantly to discuss supports we want to talk about caregiving

10:14:43 in 2018 caregivers [Reading PowerPoint]

10:14:55 so that is unpaid assistant

10:15:12 direct care workers provide the majority of caring homes and in healthcare settings, and it often cases the staff have to support themselves and person centered care.

10:15:24 Person centered planning, person centered thinking provided meetings to help support providers provide both what is important to the person

10:15:30 as well as what is important for the person with living the dimension.

10:15:44 With that I would like to turn us over to panel discussion which will be led and facilitated by Rev. Cynthia

10:15:57 Dr. Huling Hummel 's

10:16:10 she rep helps represent the 5.8 million Americans living with dementia, she has been an Alzheimer's research participant for 10 years.

10:16:19 She hopes to serve international organizations as an artist and author, she also sings in a country band.

10:16:32 She will be moderating our discussion and with that, thank you Cynthia for joining us and I will turn this over to you to invite the rest of our panelists to join.

10:16:36 >>CYNTHIA: Thank you so much and hello everyone.

10:16:50 It is my joy my pleasure to be with you today, I would like you to be introduced to Brian Van Buren,

10:16:59 he is an advisory Council member for dementia alliance.

10:17:20 He reimagined himself after his dimension diagnosis. As an African-American man he felt like he needed to give a face to the disease and he felt the need to address marginalized populations.

10:17:38 Next is Cameron J camp, PhD who originally developed an adaptation to help people with living with dementia

10:17:46 he currently serves as the director of research and development for the center of applied research in dementia.

10:17:55 He gives workshops internationally on cognitive and behavioral interventions to reduce the challenging behaviors

10:18:01 an increase the level of functioning and quality of life of persons living with dementia.

10:18:15 And then I'd like to introduce you to Elias Rodriguez, a registered nurse who works as



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a community life director for a senior living community.

10:18:31 His back practices has made him an advocate for quality care, as an ambitious ankle motivated breeder he spends his days be seeking the highest quality of life for employees and residents in his community.

10:18:37 We are going to spend the next 10 minutes or so just with a little bit of reflection

10:18:47 I would like to invite the panelists to reflect on these questions, Brian going to start with you.

10:19:00 How did you get involved with advocating for person centered supports for people living with dementia, and how to do the different parts of your identity

10:19:13 for example Ray sexual orientation, how did that shift your perspective on person centered supports for people living with dementia, and why are you so passionate about your work?

10:19:17 We need to unmute you my friend.

10:19:23 >>BRIAN: Okay.

10:19:30 Hello everyone, my name is via Brian Van Buren.

10:19:39 I currently live in Charlotte North Carolina, the rest the time is Rio de Janeiro with my husband in Brazil.

10:19:44 Because the virus I've not seen him since March so I am basically living alone.

10:19:50 I became an advocate because I began to see a need.

10:20:02 When I first got my diagnosis and I was appalled because African-Americans diagnosed with dementia at a higher rate, but I never saw another African-American

10:20:05 in any of the events that I would attend.

10:20:14 I was luckily enough to have an African-American couple come to Charlotte to do a book seining.

10:20:25 Very well-known couple, he was the first black model on many many magazines, she owned restaurants

10:20:33 in various stores and she was a frequent guest on the today show where she could cook demonstrations.

10:20:41 So she was doing a cooking demonstrations that she had done 20 times and all of a sudden couldn't remember what she was doing her where she was.

10:20:47 That was a start of her journey, shortly after that she got diagnosed with all timers.

10:20:55 They felt that it was very important to get a face to all timers to assist people in the African American community.

10:21:06 So I went to the book signing and after they spoke I stood up and announced to the room that I had just been diagnosed with Alzheimer's, and I burst into tears.

10:21:16 And then they came down from the stage and embraced me and held me, and he said that I got you my brother"

10:21:29 he held me for about five minutes, and then he had said "you have done something very great you've given a face to this disease, I am very proud of you, but now you have a responsibility

10:21:37 to go out and show that face to the world so that they can see that you are a person who is living well with all timers".

10:21:42 What was the other part of the question Cynthia?



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10:21:57 >>CYNTHIA: I'm just curious, how did you, once you got your diagnosis, how is that shaped your ideal of person centered supports?

10:22:06 You know you get your diagnosis from a doctor and you leave the office, what were you longing for her hoping for when it comes to support?

10:22:15 >>BRIAN: I was lucky enough to get on the computer and find the old-timers Association

10:22:19 and they have a chapter in Charlotte

10:22:28 people who were early onset, so I got involved with that group

10:22:39 that led me to get involved with 70 different groups, I have been invited to so many conferences and TV radio magazines newspapers

10:22:47 last year went to South Africa and did the first memory café that they have ever had on all timers.

10:22:57 This is become a passion for me, prior to my diagnosis I was an international flight attendant for 20 years.

10:23:03 People think of that is a glamorous job because you're in Paris one week in Germany the next

10:23:14 But the reality is very sad and lonely profession. I did it for 20 years and to be honest with you I just existed.

10:23:24 I didn't have any kind of life, many people found it strange but being diagnosed with Alzheimer's that has been the best thing is ever happened to me.

10:23:28 Because it gave me a purpose and it gave me a person to get involved.

10:23:37 And I've just really really enjoyed what I am doing, and a number of people that I have met

10:23:46 I know that I am helping and I am assisting people so that is my new calling. And it's great.

10:23:59 >>CYNTHIA: I'm so grateful for your friendship and for your advocacy, I want to move on and see if Cameron would like to reflect on the question that I asked for Brian.

10:24:07 In terms of how you have gotten involved in advocating, where you are so passionate about caregiving?

10:24:10 >>CAMERON: Sure.

10:24:17 My original research was working with younger and older adults and teaching them how to remember things better.

10:24:24 And then I moved to New Orleans and began doing work in the adult day centers.

10:24:33 In Louisiana, Kenner, they had the first day center in the country specifically for people with dementia.

10:24:43 And so I came in there and everything that I had tried to do in the past that was successful, was now useless.

10:24:47 In terms of how to get people with dementia to remember things better.

10:24:54 All the mental imagery and all the things that required a lot of effort, just did not work.

10:24:57 And so I had to find a different way.

10:25:05 At the same time my children started with a story school.

10:25:10 I walked into this classroom and learn saw how these children learn by doing.

10:25:17 They learn to a different memory system, whether it's unconscious learning and



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effortless learning.

10:25:24 So I brought a neuropsychologist that I knew into the classroom and asked if this is the way forward?

10:25:31 Not only did he say yes but he also enrolled his children in the school, and I was an epiphany for me.

10:25:44 I'll give you an example, I was at the data center and there were a group of women there who are white, everyone there had dementia, and new client came an African-American male

10:25:58 he walked over towards these women and they told him to go away, they called him a number of racial slurs, the staff went over to him and asked them why they could treat this man this way

10:26:07 how could you call yourself Christians and treat a man like this, and they said yeah you're right you're sorry it won't happen again

10:26:24 And so again that memory went away and it happened again

10:26:30 so do you ever give things to people that you like to receive?

10:26:33 You have games and prizes.

10:26:44 Let's rig the games and let the women win everything for the next two weeks, however for this moment on this man in this new client

10:26:48 he gives out all the good things at the center.

10:26:53 So all good things flow through and only directly through him.

10:27:05 This is an example of an unconscious learning system, this is called a conditioned emotional response, the feelings that a person elicits by how they interact with you

10:27:07 become associated with that person

10:27:14 even if you can't remember episodes you can learn to like someone learn to hate them

10:27:17 based on how they consistently make you feel

10:27:23 so I came back in a month and asked if they were calling him names anymore?

10:27:33 But no now he is their friend and he is always been their friend, they go way back. What was happening was that they were learning to like him.

10:27:43 They were trying to figure out why they should like this guy, and the urban legend group say I've known him for a long time.

10:27:50 It was a simple thing but it was a way to change the nature of that relationship.

10:27:56 So we been using this approach for a long time, and a lot of different places.

10:28:11 My wife and I were visiting a nursing home in Switzerland, where they use the monastery approach, where the people with dementia decide what they're going to do that day

10:28:20 what social causes they're going to support, how they're going to take care of their own community, where they want to go for outings.

10:28:31 And to the people living there read us a welcoming speech in English, because they were taking an English-language class

10:28:36 taught by another resident who speaks multiple languages.

10:28:46 And I'll never forget the ending of their speech, they said we want to thank you for giving us our liberty back.

10:28:52 So this is, you can't have those kinds of experiences and not be changed.



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10:29:03 And so this is what we are about, this is about human rights and it's about liberty. When I am in France I always say

10:29:17 you have these words on your flags and under buildings, liberty, equality, fraternity.

10:29:34 So it's always been about human rights, person centered care, she was nominated for the peace price three times because she was an advocate for human rights

10:29:43 so that's sort of my background, my wife was a Montessori teacher for 30 years.

10:29:47 It's a way of living. And that's where about.

10:29:50 >>CYNTHIA: Thank you.

10:29:58 Elias I would love to hear from you and what has captured your passion about this work.

10:30:08 What is it, that brings you such joy to advocate for person centered support?

10:30:19 >>ELIAS: Hi Cynthia thank you so much. I can tell you that I am a trained registered nurse, I went to nursing school.

10:30:28 As I went to nursing school I feel like I got the basic training that most nurses likely get,. But we kinda skimmed over dementia.

10:30:36 We learned a little bit about what it entailed, and then we went out and did our clinicals

10:30:43 after I graduated I got a job in in-home care, doing home visits throughout the community.

10:30:47 I had asked several expenses with people living at dementia.

10:30:52 Most of the training became from other nurses that have been in the field for long time.

10:31:00 So I realize a lot of the ways they approached the persons living with dementia, from nurses that have passed on their knowledge and experiences

10:31:05 and that's how I was navigating my nursing career.

10:31:19 I was given the opportunity to work in a senior living organization, so when I arrived here we had several members of the community who were persons living with dementia

10:31:27 and soon after on a fateful day working with a consultant group, Monarch pathways.

10:31:39 They happen to connect us with an wonderful man, who is Dr. Cameron camp who walked through the doors with the ray of light

10:31:44 and he had some new approaches.

10:31:56 We're talking about Montessori, which as always been on for schools, but we learned it was a new approach.

10:32:04 It was an earth shattering and it wasn't difficult, it was just a new approach that we sell things change very dramatically with.

10:32:13 What I noticed is that it is a person centered approach if you look at these people as individuals instead of groups

10:32:21 that really changed everything from that moment on, so we personalize things to each individual person

10:32:27 their response was so much better for both parties, was a pleasant expense for everyone.

10:32:44 It really happened on day one, we get a little bit of the training and started learning about the Montessori inspired lifestyle, our interactions





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10:32:56 were good and pleasant. So if I asked myself how I would like to be approached her home how I would like to be asked, what the things I like to do

10:33:04 I think one of the things you asked was, what kind of things my own identity like you asked Brian.

10:33:15 I love Star Wars, I love competitive boardgames, I hope that I can have that incorporated in my care, I want to have those things in my room.

10:33:32 I realize that those little personalization things go a long way both in trust, in the emotions and the bonds, and everyone has a better experience every day is better as a result.

10:33:36 >>CYNTHIA: Thank you so much for your insights.

10:33:45 You can really feel the passion when you talk about how it made it difference in your work environment, and day-to-day interactions.

10:34:02 I was thinking of my own experience when I was diagnosed in 2011 with mild cognitive impairment due to Alzheimer's.

10:34:07 There were a whole lot of time things set up for people living by themselves.

10:34:11 But also for people who had a dementia diagnosis.

10:34:20 So I was just curious, and will carry this back to my friend Brian if we may.

10:34:26 Since you have a few more minutes, Brian your personal lives alone

10:34:36 we talk about person centered care, did you run into any obstacles looking for the care that you wanted?

10:34:44 So often at least in my experience, trying to find a place where I can get some support or some care,

10:34:51 I was limited by the fact that I lived alone, Brian what about your expense?

10:34:55 >>BRIAN: I put together a treatment team.

10:35:01 Ida speech therapist general practitioner and a pathologist.

10:35:05 I had support from pretty much every other corner.

10:35:10 And it was important to have all these people in my life because they really assisted me.

10:35:21 When I first got diagnosed I could barely speak a sentence because my memory was gone, but she worked with me for about six months

10:35:30 so I was able to get my speech back and once again be able to talk, and she helped with my cognitive skills as well.

10:35:36 It's available out there you does this have to know where to go and no were to look, and go for.

10:35:46 >>CYNTHIA: we have to learn to be advocates for ourselves, to ask for what we need

10:35:53 but also knowing about these awesome resource NCAPPA

10:35:57 I'm wondering as we look

10:36:06 T panelist for your insights on this, if there is one lesson that you've learned in this journey

10:36:13 the strategies that you found that work for people, that help make that person

10:36:22 so guess there's two pieces that question, Cameron Woodhead lesson have you learned in this journey, and what makes something person center?

10:36:29 >>CAMERON: The most important things that I've learned is that persons with



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dementia can still learn

10:36:41 it depends on how they're taught, but persons with dementia can still acquire new habits, new skills, they can also recover function

10:36:55 you just heard from Brian about regaining speech capacity, I know of instances for example where physician would not write a prescription

10:37:03 for rehabilitation for a person just because they had a diagnosis of Alzheimer's disease.

10:37:12 The justification was is that while they have Alzheimer's they can't learn anything new, so rehabilitation in these services would be wasted on them.

10:37:21 And this was for a friend of mine, who had been a medical director, had a long term care community.

10:37:29 And he was not being given this prescription for rehabilitation, for me this is personal.

10:37:49 fighting against that stigma, and fighting against the negative stereotypes that are out there and that are prevalent is really what I've learned

10:37:53 has to become my cause.

10:37:57 I don't have a job, I have a mission.

10:38:04 There is a difference, and it is admission, it's about changing the way people think.

10:38:17 It's a revolution in the sense that Gail Leo said that the earth is now the center of the universe, the sun is the center of the earth revolves around the sun

10:38:20 this was a revolutionary idea.

10:38:22 Change the way people thought.

10:38:32 Persons centered care, it's a revolutionary idea because we revolve around the person.

10:38:44 That was my awakening, and I remember my wife and I having dinner with an old friend named Christine Brighton

10:38:50 in Australia who's written a number of books on living with dementia,

10:38:57 the last one being nothing about us without us, that was its title.

10:39:06 She was assigned by the Australian prime minister and she said, when I was giving my diagnosis, my neurologist

10:39:12 basically wrote me a prescription for disengagement from life.

10:39:21 And he said here's the things you will be able to do anymore, and he listed them, but she told him to go to hell.

10:39:24 >>CYNTHIA: Good for him.

10:39:31 >>CAMERON: But she got a new business card and surprisingly enough it was advocate on.

10:39:38 So she went on to go be a great advocate for people living with dementias.

10:39:46 Encountering those rebellious spirits along the journey also has been awakening for me.

10:39:59 Just personally I have a daughter and her 40s who is learning disabled, so I'm a lifer with dealing with people with cognitive disabilities

10:40:09 so it's all front and center, but meeting these amazing people and having these experiences is just been really pushing this into high gear.

10:40:16 It's time for a change, it's time for a revolution in the way we think about dementia as



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a society.

10:40:20 >>CYNTHIA: Thank you for your insight.

10:40:28 I'm in ask Elias, what are the strategies that are working well for you and the perfect people that you serve?

10:40:34 And if you have one lesson the share, can you share that with us?

10:40:38 >>ELIAS: I member per having a pretty powerful experience.

10:40:45 But it was changing the way I thought, but that changes the way that you approach future situations.

10:40:54 We had a meeting group, I think we had eight community members residence, all people living with dementia.

10:40:59 We were going to have a reading group, and people were randomly selected.

10:41:12 And Dr. Cameron came didn't have background anything, so one of the committee members there who was there for a few years, he didn't speak and he didn't really understand or listen

10:41:21 and so, they were part of the group, and we were discussing how goes.

10:41:28 What happened was they gave each of them a book or pamphlet, that had large plant

10:41:32 spaced out, easy-to-read booklets.

10:41:44 And to everyone absolutes shock, not only did she read it but she read it beautifully. We never even heard of you voice before.

10:41:56 It was as of the way we are communicating, I thought we could be auditory, reading turned out to be something that she really enjoyed.

10:42:01 And so we started writing communication and getting responses.

10:42:07 It was jaw-dropping, that experience was eye-opening

10:42:15 thinking differently, approaching differently and maybe trying something and you haven't thought of.

10:42:22 Trying to use multiple different ways of communicating, instead of saying that they can't respond when you ask a question.

10:42:30 That was the way he was approached in the past, before we were person centered.

10:42:41 I say the way to approach and ask questions, the way to think, some of the strategies have been in preparing that environment.

10:42:48 Making that opportunity for success, making his high opportunity for success is possible.

10:42:56 And that comes from knowing the individual in making a person centered, personalized approach to give than the best opportunity

10:43:04 and then you start building confidence, and you're more likely to try sending different and try something new.

10:43:07 Try something that may have been uncomfortable for.

10:43:15 But having that trust is how I think that we have been able to see some of our community members

10:43:20 really thrive in ways we didn't think that they would have before that.

10:43:24 So preparing the environment.

10:43:33 Asking in a way that was, would you instead of could you.

10:43:41 Remember that it doesn't take a lot of effort, it's a human experience in a way of



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approaching people in a kind loving way

10:43:46 the way that I like to be approached in the way most of us like to be approached.

10:43:59 It creates an emotion, that Dr. Camp Was saying previously that they will remember

10:44:03 So it really helps long term as well.

10:44:11 >>CYNTHIA: It sounds like communication is key, not making things about what people can and cannot do.

10:44:15 >>ELIAS: Very much.

10:44:22 >>BRIAN: I left one person on my support team, that is my life coach.

10:44:27 Her specialty is working with people with dementia and Alzheimer's.

10:44:33 Things like agitation and depression, various other things like paranoia.

10:44:43 I'd be paranoid the people would be out to get with me, so I would sit down with her and she was able to focus me and help me realize that what is

10:44:45 I was imagining was not real.

10:44:49 That was one of the best things for me.

10:44:56 I just went on the computer and looked up what life coaches and I found this woman, and she is help me get through

10:44:58 this disease.

10:45:07 >>CYNTHIA: I was going to ask you if there is a lesson that jumped out to you, that you would like to share with other people.

10:45:20 Maybe somebody is going to a doctor tomorrow who may get a dementia diagnosis, what is one of the lessons you want to share with the moving forward?

10:45:24 >>BRIAN: Don't believe the doctor.

10:45:28 Quite often the doctor will tell you to go home and get your affairs in order.

10:45:33 They give you no assistance whatsoever in living your life with Alzheimer's.

10:45:35 Life does not and.

10:45:42 So unfortunately you have to really and get out and seek it yourself.

10:45:50 It's available and it's out there, and a lot of people who are supporting you

10:46:00 because this disease is so well-known, I wear a button that says

10:46:05 I have people approach me when they see my button and I getting to conversations

10:46:15 I get so many referrals for people in neurology and support groups, it even got me out of afforded our speeding ticket.

10:46:23 I was driving down the road and, the speed limit was 35 and I was going 60 not paying attention

10:46:30 I looked up and saw lights, but the policeman came up to my window with the registry to license please

10:46:33 he said you know this is a foreign dollar ticket.

10:46:37 See him back to his car and I said oh well I'm toast.

10:46:43 Came back and he looked at my button a couple of times, he asked me why I was wearing the button.

10:46:47 So I explained to them what it was like to live with Alzheimer's.

10:46:54 He told me that his mother was showing signs of what he was talking about and asked me if she should be tested.

10:47:01 And I said yes, and he said thank you and have a nice day and forget about the ticket.



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10:47:04 >>CYNTHIA: That's a great story.

10:47:15 I am very curious, life is change were so many of us through this pandemic, I'm curious how it has affected your experiences

10:47:25 of living with dementia and in Brian's case of working with people who have dementia.

10:47:33 I'll start with you Elias, how has person centered supports looking feel different now

10:47:43 when you look at COVID-19 19, how are things different for you in your community did you work with everyday.

10:47:51 >>ELIAS: I would say that the pandemic definitely further changed our perspective and our approach.

10:47:59 One of the things about having the Montessori inspired lifestyle, it has prepared us to have that individualization

10:48:09 sewer able to get a lot more information and ask a lot more questions, to be more person centered and more personalized when someone moves in.

10:48:14 So that way we can do our very best to personalize their care.

10:48:24 So in this instance when someone moves in, during the pandemic when they're not able to see their family members as frequently as they would normally want to

10:48:33 some of the people would see their family every Sigel day, that wasn't a possibility during the pandemic

10:48:36 so we had to start thinking about thinking outside the box.

10:48:46 We have technology at our fingertips, should we use technology

10:48:52 And how do we incorporate the family members and the individuals in that process.

10:49:00 So we had a display set up to do video chats, we tried zoom, we tried face time on the iPhone and iPad

10:49:09 and it allowed us to bridge the kind of a gap between seeing someone in person and having the ability to commune a cave with family

10:49:18 we notice that the first time it happened, it was an awkward conversation, avian awkward experience

10:49:27 but as the frequency increased the comfort really grew and people were able to have great conversations

10:49:37 laughing, "I miss you" I love you. Having real conversations.

10:49:43 We are all skeptical, not knowing if this would be a good way to compensate.

10:49:53 But as long with religious services, our community members that have religious background who want to attend services but can't because the pandemic

10:50:03 we are able to find creative ways through streaming services, face timing with pastors that they may have had in the past and feel comfortable with.

10:50:12 Doing things that allow them to have some kind of relative human authority, in the ever-changing environment of coven.

10:50:16 It allowed us to be adaptive.

10:50:26 And knowing the community members that we have living with dementia, knowing that they are able to change and we gave them the opportunity.

10:50:29 So they could jump along with us.

10:50:34 >>CYNTHIA: Thank you for the insights of your sharing.

10:50:47 Brian, how do person centered supports look different between pre-coven times and



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today.

10:50:50 How if things change for you?

10:50:56 >>BRIAN: I belong to an international group called couch surfing.

10:51:06 I was living alone and isolated, it's a very similar organization as air B&B but it's free

10:51:10 there are people asking Vegas crash at your place.

10:51:24 People from all over the world in different occupations, for the last three years of it over hundred 20 guests stay with me, but since the virus, I haven't had any guest since March.

10:51:28 I am really longing to have that interaction again with people.

10:51:32 I do have two roommates who really helped me.

10:51:39 I talked to Alexa every day, and she is pretty smart.

10:51:49 But one of the things that she does for me is when I come into the house, I tell Alexa where I put my keys, she tells me when to take my medication

10:51:51 she tells you when I have meetings

10:51:56 she's a great roommate, you don't have to fight with her.

10:52:06 But that has really helped a lot, and then as far as medications are concerned, I'm on 13 different pills.

10:52:13 Initially they wanted to send me 90 day supplies, for 13 different prescriptions.

10:52:20 So you can imagine how much difficult it would be, this pill in this box and this box in this box

10:52:27 so at a home health nurse come in, Medicare said I had qualified.

10:52:37 She turned me onto a pharmacy that bubble wrap's my medication, so all I have to do is punch out the day and take my meds in it so much easier.

10:52:41 Technology and various other things work.

10:52:46 It's also moved to make places dementia friendly.

10:52:54 We are working on making airports dementia friendly, very difficult to travel when you have old-timers.

10:53:16 But I have a business card that I give to the customer service rep to tell them that I have all timers, they let me board early and they have someone meet me and take me to make next gate

10:53:20 >>CYNTHIA: Thank you my friend.

10:53:33 Cameron, with regard to COBIT 19, now we are in the midst, how if you noticed or what have you noticed in terms of how things feel different

10:53:39 with regard to person centered care, working with people as setting up a plan.

10:53:42 What is changing your mind?

10:53:54 >>CAMERON: I think the biggest change, the biggest challenge, is that you can't literally see in person.

10:53:56 The people that used to see.

10:54:05 And that disconnection in terms of social links has had a really profound impact.

10:54:12 Not just with the person with dementia, but also for the people would living with them.

10:54:20 And places where Elias works where the staff may not be able to see each other like they were before.

10:54:28 This disconnection, the social disconnection has had a profound impact, it's a human thing.



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10:54:34 When you add onto that memory deficits, that makes it even worse.

10:54:41 So once again it's about finding ways to circumvent the deficits.

10:54:58 So for example for some of our colleagues in France who worked with their clients with dementia, to come up with some signage that describes what COVID-19

10:55:07 Is been very straightforward terms, why people are wearing masks, why people can't visit like they used to

10:55:12 so that it can be a will reminder about why things are the way they are.

10:55:22 Also, if you have a mask it also helps to have your photograph next year name, so people understand who you are.

10:55:32 Little things like that to get past some of the fear that a masked person coming into your room can exhibit.

10:55:46 But there is another thing and that is, sometimes I hear people say we don't want to make people with dementia afraid and tell them about COBIT 19

10:55:51 as if they have to be protected from reality in the world all the time.

10:56:02 What we are seeing in other places, that would take a different approach, like where Elias works, these are persons

10:56:05 that have been through so many other things.

10:56:14 I'm ever being in a high school gymnasium as a child getting vaccinated for polio, and what that was like.

10:56:18 Well we were afraid to go to swimming pools before that.

10:56:27 And these people who have lived through these things, through so many crises and depressions, these are our resources.

10:56:34 Sometimes our staff has had chats with persons with dementia one-on-one

10:56:36 and asked them how they got through it.

10:56:40 What gave them the strength to keep going on?

10:56:42 How did you survive?

10:56:48 It also gives us an opportunity to make these very human connections.

10:56:55 To look at a person who may have dementia during this time of the pandemic as a resource.

10:57:00 As a repository of wisdom, and life experience.

10:57:03 That they can share.

10:57:17 So giving that opportunity both of the person with dementia and the person who is younger, it's an opportunity to take in the manage of it.

10:57:22 Knowing of the person.

10:57:28 Again, always cycling back to person centered living.

10:57:37 >>CYNTHIA: Elias I'm going ask you a question about, is there something that is happened during this pandemic,

10:57:45 if there might be a positive change that you would see retained, or may be continued beyond the pandemic?

10:57:51 Something in you maybe didn't see before that we have now embraced, something you want to consider for continuation?

10:57:56 >>ELIAS: One of the things we focused on quite a bit was purpose.

10:58:06 People who had a lot of purpose before the pandemic, who were involved in groups



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are doing things, or who are advocates of bridge.

10:58:11 Bridge was almost a religion, they had to play twice a day different times.

10:58:14 So is finding ways to just still have purpose.

10:58:21 One of things that has come out of this is involving community members, residents who live here in the problem-solving.

10:58:27 And having that really open discussion with some of the difficult conversations

10:58:32 related to visits, at least in California where I'm from.

10:58:41 It is been very stringent as far as visitors being able to enter places like the ones where I work.

10:58:50 So having to adapt to these situations, we decided to incorporate the community members every step of the way.

10:58:59 As a result it created a great solution, that everyone was involved with and everyone was happy with the end of the day.

10:59:07 When it came to having to modify it because something came down through the department of health, again

10:59:10 incorporated and reevaluated.

10:59:21 It is been a really wonderful way to have this great communication, and work with staff and community members all throughout

10:59:31 in a really think it's going to continue, whether it's going to be what do you want for breakfast in 2022?

10:59:39 Or something else, we are always gonna be able to incorporate these medication pathways that we have developed.

10:59:49 >>CYNTHIA: I love that your involving the residents in your community, and asking about their ideas. Asking the community to weigh-in.

10:59:57 I must give them a bit of esteem, to great idea.

11:00:08 Brian I would ask you my friend, do you think there's something is changed in the pandemic, a positive change that you would love to see continue on

11:00:19 We need to unmute you.

11:00:29 >>BRIAN: I can't think of anything at the moment but I will let you know.

11:00:38 >>CAMERON: I think the combination of realizing that the persons with dementia can learn.

11:00:46 Realizing they can utilize technology with assistance, to be able to communicate people with a distance.

11:00:50 I think that has accelerated their coven.

11:01:01 As Elias was talking about, it's a step-by-step project, but you get small increments of improvement until a person can be comfortable with the new technology

11:01:03 even though they have dementia.

11:01:11 I also think because of COVID-19, people may cherish their relationships more.

11:01:17 People may cherish the opportunity to connect, more.

11:01:25 I will never personally ever take for granted a visit with my grandchildren.

11:01:37 Two not be able to see them and to hold them, and to at least be able to play Candyland with them on FaceTime.

11:01:44 I will take that, but when I can see them in person





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11:01:53 I will be different in the way that I think about and how I feel, like I did before COVID-19.

11:02:01 >>CYNTHIA: I was reflecting on your comment about how people dementia can learn new skills, technical skills

11:02:12 I was thinking that my old church had asked me to learn to Facebook live, so I can preach the services, they were looking for my assistance

11:02:23 we had to go through all the steps, I had to write them down, I had to practice in the beginning, I couldn't have any chats up because it was too distracting

11:02:28 I had to have metal cart up there and eventually once I was familiar with all the steps

11:02:33 then I could start peeking occasionally to see who is on or who was saying something

11:02:38 but giving people a chance and opportunity to try and learn new things.

11:02:40 Thank you for sharing that.

11:02:45 Would any of the other panelist like to share any other ideas?

11:02:54 On how we can continue to embrace different ideas for person centered care?

11:02:59 During the pandemic or beyond the pandemic?

11:03:05 >>ELIAS: Vacation is increased otherwise.

11:03:14 People who earn may be visited once a month, are now calling every day. That is likely market indication then some people

11:03:20 so there has been increasing indication otherwise, even though nonperson.

11:03:30 There is quite a few family dynamics that have been strained, maybe they were not talking anymore, maybe they have issues

11:03:38 but they have resolved, people have decided that it is pointless to continue being upset about something that happened years ago

11:03:44 we seen a lot of resolutions, we see lot market indication on the phone and video chat.

11:03:52 I think it's in some ways, it has mended some of the relations that may not have been amended otherwise.

11:03:58 So there have been some great progress if we keep an optimistic guy.

11:04:08 >>CYNTHIA: Last thoughts as for everybody has begin to wind down, if you have anything else you'd like to share, a word of wisdom

11:04:13 a and experience, that may help another organization.

11:04:20 That will help someone who is dealing with a dementia diagnosis.

11:04:26 You're on the screen the last one we start with you and then go with Cameron and let Brian finish.

11:04:30 >>ELIAS: All I can say is just try.

11:04:39 It doesn't hurt to try, give it your best effort,, try something new, asking a different way, approach it

11:04:42 with the opportunity of for success.

11:04:47 How can I make this as easy and as best as possible?

11:04:56 Remembering that at the end of the day it's a feeling for both parties. It is a kind and human approach.

11:04:58 It's wonderful to just give it a try.

11:05:01 >>CYNTHIA: Cameron last words?



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11:05:11 >>CAMERON: I was talking to someone who is a caregiver at home, for his spouse who had early Alzheimer's disease.

11:05:22 The caregiver was saying that he kept putting up signs that say don't do this, and they would do some thing else and putting up more signs

11:05:25 sin is like playing lacrimal.

11:05:29 He asked me what he was supposed to do?

11:05:37 I said perhaps if you put up signs to encourage them to do things that they can do.

11:05:43 Perhaps if you guided them, in terms of how they can contribute.

11:05:45 Why are they doing this?

11:05:53 Because they want to contribute to the household and the family, they want to have purpose, they want to do things.

11:06:01 You are telling them what they can't do, and then asking them to figure out what they're going to try next.

11:06:11 We should not be surprised at this. Let's look at the strengths that your spouse has, let's look at the social roles that they can do based on those strengths.

11:06:18 Let's guide them in terms of time and place of when they can do these things, how they can help you in meaningful ways.

11:06:25 Let's focus on who this person is as opposed to what they have lost.

11:06:29 >>CYNTHIA: I like that message a lot.

11:06:39 So often when someone gets a dementia diagnosis, people tell them that you can't drive you can't work, telling all the things that they can't do

11:06:42 instead of telling him the things that they can do.

11:06:47 >>BRIAN: I noticed in the chat rooms is one of the things that people asked,

11:06:54 why aren't there more people on panels and webinars who have dementia and old-timers?

11:06:57 Believe it or not that is really changed a lot.

11:07:02 Through dementia action alliance.

11:07:09 People with Alzheimer's of the experts, not just the people with all the letters after their name.

11:07:18 So they've really pushed to include us in so many things, you can tell them a little bit about the white paper.

11:07:31 >>CYNTHIA: Brian and I are both serving on an advisory panel for a study,

11:07:35 we are put together a survey of people living a dementia.

11:07:41 That will inform the advisory committees research.

11:07:53 So we have the opportunity to interact with researchers and it has been well received.

11:07:56 And how we are still able to make a difference.

11:08:02 Focusing on the positives, but thank you for bringing that when O'Brien.

11:08:06 Well we are coming to the end of our time here.

11:08:17 We're going to turn the microphone off back I believe to Bevin is going to come on next and talk about, or address some of the Q&A.

11:08:20 >>BEVIN: Yes right.

11:08:26 Thank you so much Cynthia for your great conversation, and your facilitation.

11:08:33 I appreciate you, and Brian Cameron, and Elias.



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11:08:37 We've had some really great questions and chat and I've been jotting them down.

11:08:40 If you have other questions feel free to put them in.

11:08:47 I am pretty certain we will have more questions and we will have time to answer, but never fear we will

11:09:02 as we always do, we would give our panelists an opportunity to respond in a written form after the webinar is finished.

11:09:12 Thanks again, we have a family of questions, a lot of people really are just looking for resources and information

11:09:22 someone said that their family had been noticing signs in their mother, asking about a do address it.

11:09:34 Also a couple of questions around, peer support groups for people living with dementia, and also for family and caregivers.

11:09:42 First I want to give that to all for review if you could share some of your go to resources, and advice you would give someone

11:09:48 but before we do that I would also like to invite, anyone to put into the chat.

11:10:00 Because you have lots of knowledge and so we can outsource this question. So if you could also just put your resources in the chat, we can compile of those and put those together.

11:10:06 Cynthia now that it table is been turned you, once you go first.

11:10:15 >>CYNTHIA: I also get the question about what I should do, people are nervous about their spouse or their parents are themselves.

11:10:23 I always encourage people to make a appointment with her primary physician, with their provider and get them to check it out.

11:10:33 To have a thorough examination, to eliminate what things are, not jumping to the conclusion that you have a diagnosis.

11:10:40 Also the Association has a 10 warning signs is one of the resources, we can put a link to that.

11:10:50 It is a little handy guide that can be a way to guide the discussion if your time is limited, to show your provider that these are the changes and challenges

11:10:53 and I can serve as a benchmark.

11:11:00 But it's always important to get things checked out that's my 2 cents.

11:11:08 >>BEVIN: Any word on peer support groups and you are familiar with are comfortable with?

11:11:12 >>BRIAN: I belong to several support groups.

11:11:21 I belong to a African-American support group, initially the Alzheimer's Association tried to start a group

11:11:25 but that white facilitators and nobody came.

11:11:36 So someone got a bright idea and had an African-American facilitator, so that group has about 30 people that meet once a month

11:11:42 we have guest speakers, we have books for people to read.

11:11:50 This is given a lot of information, because lot of African-Americans have no idea what to do when they have a diagnosis.

11:11:55 The doctor doesn't tell you what to do,. so we can assist that.

11:12:03 The sad part however is for many African-Americans, they keep it a secret like it



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something that they should be ashamed of.

11:12:10 That's just the history of the African American people, we don't share what goes on stage in your house.

11:12:13 Especially when it comes to medical things.

11:12:19 I am a strong advocate for research studies.

11:12:28 Partly because my grandfather was part of the Tuskegee study, he died in the 50s from syphilis.

11:12:38 So a lot of African-Americans are suspicious to the medical system, but what I say is that is that that was something in a very dark period in our history

11:12:45 but we need to move forward, because we need to have participation of all races in the studies.

11:12:49 >>BEVIN: Well Ryan.

11:12:56 >>CAMERON: There is a group called dementia alliance international.

11:13:03 They advocate for human rights, and for the rights for persons with dementia.

11:13:10 They have a voice with the world health organization for example.

11:13:16 So dementia lines international is a nice group to find out more information about.

11:13:29 >>CYNTHIA: Brian and I are both on the advisory Council, it's a great group, activities support and services.

11:13:34 A lot of opportunities to participate in many different ways.

11:13:42 There is a number that the Alzheimer's Association has as well, to 24 hour hotline.

11:13:54 And that is for anyone who has a question about people with dementia, it's helpful for care partners or with people dementia.

11:14:06 But there's also different groups that specifically help people who have those diagnoses, we can forward that information as well.

11:14:12 >>BRIAN: One thing I wanted to say is that there is no charge to participate in any of these support groups.

11:14:20 >>CYNTHIA: That's important, and many are led with people with dementias that's important as well.

11:14:26 >>BEVIN: Eliasson ThinkPad.

11:14:31 >>ELIAS: I was really good I feel embarrassed to even talk.

11:14:39 I would say the local research hospitals, any in your area they have a variety of support groups if you go to their website

11:14:45 you can usually find a support group related to your specific diagnosis.

11:15:01 >>BEVIN: just so you remember we have a ton of crowd source resources, if you put in something please select all panelist and attendee so everyone can see it

11:15:05 but regardless we will be compiling all of these and posting them online.

11:15:15 And for people who are joining late this is recorded as well as the slides will be posts of our website and a couple of weeks.

11:15:17 Onward.

11:15:27 I have a question Cynthia, that I would like you and Brian also to respond to.

11:15:30 And everyone else if you would like.

11:15:36 We had a questions about being curious how the church is involved.

11:15:40 The church community's involvement in your circles.



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11:15:49 The question was initially free Brian, but I figured Cynthia also has the background and you might build answered as well.

11:16:00 >>CYNTHIA: As a pastor delights me to see so many communities involved in dementia friendly community activities.

11:16:13 Many of our houses of worship will have memory tests, or have times to have people come and participate.

11:16:23 There are lots of ways that our faith communities can involve people who are living with dementia and our care partners.

11:16:31 There are many in-house support groups, many you have people who will do respite care who have been trained to go in people's homes

11:16:35 some have special services for people with dementia.

11:16:42 As you know every year I leave the service on world dementia day

11:16:52 so remember people living with dementia, there are many different ways of congregations being involved.

11:16:59 I am by people to reach out to their own faith committee and talk about what you can do.

11:17:07 Even in the time of the pandemic there is time ways to connect and make things easier for people living with dementia.

11:17:09 Brian overdue.

11:17:15 >>BRIAN: One of the things is if you don't talk about it, people do not know about it.

11:17:25 So I stood up one Sunday in church and announced to the congregation that I had Alzheimer's, believe it or not there were nine other people as well

11:17:30 in the congregation that also had old-timers.

11:17:33 So they had formed a support group for us.

11:17:42 So I got a call and got the date from the pastor checking on me, a couple of weeks ago I went to church with my clothes inside out

11:17:49 one of the church members took me aside and she said, Brian your closer inside out.

11:17:54 I was not offended and went into the bathroom and change my closed.

11:18:00 Had she not known that I don't know what would've happened, but those kind of supports are really wonderful.

11:18:19 >>CAMERON: One thing that we have done, for example when someone a priest is given communion for example, is to have some other persons with dementia next to them

11:18:27 one next to them with a sign that says holy Communion, so they understand the context of what's going on.

11:18:35 When a person understands the context it's very different than if someone stands in front of you and hold that a piece of bread.

11:18:51 And also another person to have the tray with the small little cups of water, so the person can swallow the bread without the problems with they might have

11:19:01 so by, thinking about how to accommodate, how to change the process to make it more inclusive

11:19:11 you can give people back the capacity to take part in that side of their spiritual life that is so important.

11:19:23 And also think in terms of what sorts of homily do you give, what sort of presentation,



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and the speed in which you speak

11:19:26 and the length of your sentences.

11:19:34 It is about accommodating to the people instead of asking them to accommodate to you.

11:19:43 So little things like that can make access to spiritual life much easier.

11:19:52 But it's about again person centered, how can we create person centered worship, for persons with dementia.

11:19:55 >>CYNTHIA: Amen.

11:20:05 >>BEVIN: Brian and Cynthia you both mentioned memory cafés, for those of us who don't know what those are can you enlighten us.

11:20:08 >>CYNTHIA: I'm happy to jump in on that.

11:20:19 Memory cafés are gatherings of people, they can take place in congregational settings that we've talked about in churches or other faith communities

11:20:27 but they can happen also in office foundation programs, it doesn't matter where they happen.

11:20:39 It's where people come and have a conversation have a cup of coffee, play a board game, so the people would living with dementia and pet care partners can go inside and chat with one another

11:20:47 they might have bingo, or be doing activities or some chair exercises, there a lot of fun

11:20:55 many times they are free, but again you want to call ahead in case there is an intake process.

11:21:01 You most likely want to know that you are coming and what kind of accommodations you many

11:21:08 some are welcoming to people coming alone and some require that you be with a care partner

11:21:15 so just check with your community, they are wonderful place to gather and reminisce.

11:21:19 Reminiscing is a wonderful activity as we talk about our past.

11:21:21 Thank you for mentioning that.

11:21:33 >>BRIAN: When I went to South Africa last year, we did three memory cafés in a coffeehouse and was a first time that they had ever had any kind of meeting

11:21:37 with people living with dementia and Alzheimer's.

11:21:41 Surprisingly we had almost 50 people show up.

11:21:47 For many of them they had no idea that there were not other people around that shared their diagnosis.

11:21:55 So as a way for them to network and for them to no longer feel alone an isolated.

11:22:01 To know that there are other people getting to this, it was a wonderful experience and I really enjoyed.

11:22:10 >>BEVIN: Great thank you for sharing that. It reminds me of some of the principles and ideas of care support the come up.

11:22:13 Just the power people coming together.

11:22:22 We got another set of questions that I would say were all about

11:22:33 how do you balance the sometimes conflicting goals of self determination and



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protection from harm?

11:22:44 So what if a person doesn't believe that they don't have dementia, and they are at risk of harming themselves or others?

11:22:47 For self-neglect?

11:22:57 How do we support and empower and provide services in a person centered way in the circumstances?

11:23:01 And for this one may be Elias so go to you first.

11:23:08 >>ELIAS: Yes that is deftly a high priority in the location of where I work.

11:23:18 There is something that Dr. Camp talks about witches cognitive ramps, where we trained to a point

11:23:28 In the past we may have thought that a knife is a scary item to have, something that a person with advanced dementia should not have, but

11:23:37 they have been using a knife from the majority of their life probably, they have a lot of muscle memory, it's easy for them to use a knife

11:23:44 so is having the ability to be willing to stand there and say hey let's give this a try.

11:23:50 And support them without feeling that your patronizing them in any way.

11:24:04 It's a difficult balance, but cognitive ramps and Cameron can shed more light on this, were you do reminders of the locations surrounding the exits and doors

11:24:16 if somebody likes to wander and they get anxious, if they're in the same place for long time, wandering can be a relatively dangerous thing if someone is not familiar with their surroundings

11:24:23 so we do some cognitive ramps in the exits to remind them that it's a safe place and that it's home.

11:24:31 We've also led them to have very personalized room entrances, so they can easily find a room in their work.

11:24:44 So those with advanced dementia who might have difficulty finding their particular room, we try to make it as easy as possible to make it safely back to the room on their own.

11:24:48 >>BRIAN: I have a question for Cameron.

11:24:53 How do you bring up the subject of taking away keys?

11:25:00 >>CAMERON: This ties into the general question about was talking about.

11:25:14 I would also say that is not just the dementia thing, it's a challenge that's faced by any for example physical therapist or occupational therapist

11:25:23 who wants for example to make sure, that when someone has had a hip replacement that they don't sit down across her legs.

11:25:26 Because I could go throw the surgery off.

11:25:33 How do you convince a person to do something that is for their own good, but they may not either want to do it

11:25:36 or they may not believe that they have to do it.

11:25:43 So this is a general-purpose thing, up to and including these things.

11:25:47 I'll give you a generic human answer.

11:25:59 First, if a person doesn't believe that they should do something, like not drive, or knock Claire across her legs

11:26:03 or follow a physical therapy regimen.



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11:26:15 If they don't believe that they should be doing this, then with or without dementia when you're gone,

11:26:21 they will go back to the old approach if they have diabetes they go back to eating candy.

11:26:22 We know this.

11:26:30 First it's about motivation, getting them to believe that it's in their own best interest to not do something or to follow a different direction.

11:26:33 So where they can get that motivation?

11:26:44 We said yet to find someone who they trust, who they will listen to and if you are the primary caregiver, is probably not you.

11:26:55 It's probably a physician, or a lawyer, or a banker, or clergymen, or a friend that is their own age.

11:27:06 Who can sit down with them and say listen I want to see you dead in two years, and attending your funeral, you may not believe other people

11:27:08 but I'm telling you to believe me.

11:27:18 It's one of those hard conversations that you have to have, but it helps if you'd comes from someone who is coming from position of trust.

11:27:22 Who the person believes that isn't going to BS them.

11:27:32 So then we have dementia, you also have to have that conversation present, when the individual is in their.

11:27:42 So it's easy to forget that conversation, so the record conversation, or you print the conversation, has a cognitive ramp

11:27:48 they can be brought back when the person has forgotten that, like why shouldn't I drive my car?

11:28:01 It could be something that if you drive that's fine, but if you drive your insurance is going to go through the roof.

11:28:07 It has to make sense the person about why they are going to or not do something.

11:28:16 It has very little to do with dementia, it's a human thing, with dementia just has to do with the cognitive ramps.

11:28:22 >>BEVIN: Cynthia Brian you have one thing to add?

11:28:29 >>CYNTHIA: I have a circle of people who I trust who will hold the mirror up for me.

11:28:40 I may not be the best interpreter of myself, but I make commitments in terms of driving with my kids.

11:28:50 Even though I may be kicking and screaming, but I understand that it is a from a place of love, and hopefully we can get that together.

11:28:55 But I think Cameron your ideas are very helpful for all of us thank you.

11:29:03 >>BRIAN: Cindy I have basically done the same thing.

11:29:09 I am having people to hold up the mirror, to speak the truth to me.

11:29:14 I may not want to hear it all the time but, living alone has its challenges.

11:29:16 It can be done.

11:29:19 Because you're doing and I'm doing it.

11:29:23 >>BEVIN: Speak the truth to me I love that.

11:29:31 Wow, well, our heartfelt thanks to the four of you and what a fantastic presentation.





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11:29:34 We are getting all kinds 11 the chat box.

11:29:45 I am glad for the hundreds of people who have joined us, welcome to the NCAPPS community.

11:29:49 I've learned a lot and I know everyone else has to.

11:29:54 Big thanks, Connor if you just want put up the last poll.

11:30:10 If you can do these before you go, we like to use data and information to improve our webinars, so there are quick six questions here to quickly go through before you go off to your day.

11:30:15 That'll give us some information to help us improve these openers.

11:30:23 We are taking a break for the month of December, and then we are hoping to have another webinar on January 6.

11:30:27 You get some email from us about that.

11:30:38 So thank you to everyone, particular to Cynthia Brian Cameron and Elias, and will see you guys a few weeks