

**The East Side Institute Presents: Forget What You Know About Dementia**  
**A webinar moderated by Lois Holzman with Richard Coaten, Mary Fridley,**  
**Susanna Howard and Peter Whitehouse**  
**Wednesday, November 20, 2019**

NOTE: The following is an edited transcript of a 90-minute webinar featuring Dr. Richard Coaten, Mary Fridley, Susanna Howard and Dr. Peter Whitehouse and moderated by Lois Holzman, which drew 86 registrants from across the U.S. and internationally.

**Lois Holzman (LH):** Thank you all so much for joining us. I think we're going to have a provocative, interesting, insightful conversation with four very distinguished and different kinds of people, all of whom have a passion for helping and relating to and dealing with both people with dementia and those people who are around them; their care partners, their professionals, their physicians and so on, as well as the dealing with and challenging the overall profession of medicine and its way of relating to this serious issue for the human race.

Let me just tell you very briefly about the East Side Institute. I am the co-founder and director of the Institute, which began in the mid-1980s. I'm a developmental psychologist and linguist by training; however, the Institute and I consider ourselves developmentalists. Our desire is to help all people develop and grow no matter their life circumstances, their health, their age, their socioeconomic status, their country of origin and where they live and so on. We want them to develop so that they can have better lives and so that we all together might make the world a better place. We need to grow in order to do that.

We have about 70 Associates around the world who are using what we call performance activism to work in all kinds of circumstances with people to help them make their lives better and grow and become more humanizing. We sponsor conversations like this, where we bring together people who have a shared passion for something and come from different areas and have a dialogue that might give you some insights, both practical and philosophical.

So with that, I'd like to just give a more full introduction of our wonderful people. Susanna Howard is a writer, actor, theater maker and founder of the UK charity Living Words. It runs residencies in care homes working one to one with people experiencing dementia as well as staffs and relatives. She's also the co-curator of Normal? Festival of the Brain in Folkestone, the UK, and a team member of Created Out of Mind at Wellcome. I had the privilege of participating in a workshop that Susanna and her colleague led in London this past May, so I would urge people to go to her website and to see the very beautiful work that is being done.

I also had the pleasure of meeting Richard Coaten in London at the same conference. He's a dance movement psychotherapist with the National Health Service in the UK, has traveled extensively in Europe, in the US and in Canada giving workshops and talks, and is currently the Association for Dance Movement Psychotherapy in the UK delegate to the European Association of Dance Movement Therapy.

Mary Fridley is in New York, and is pro bono director of special projects for the Institute. She is a workshop leader, teacher and former therapist. She designed and co-leads two very popular

workshops that have been given across the United States: “The Joy of Dementia. (You Gotta Be Kidding!)” and “Laughing Matters” for people of all ages of life circumstances across the country. In February, Mary was featured in *Washington Post* article called “Changing the tragedy narrative : Why a growing camp is promoting a more joyful approach to Alzheimer's,” which is what we're going to be talking about today.

Last and certainly not least is Peter Whitehouse, a professor of neurology, psychiatry, cognitive science, neuroscience and organizational behavior at Case Western Reserve University. He is truly trans disciplinary, which is something I love. His main current focus is the eco psycho-social models of brain health and aging and the role of the arts and humanities in health.

So welcome the four of you. I love that we have a medical person here, arts people, dance, literature, therapeutic work and theater. Four different people, four different views, two different countries and two different experiences. What is it that we should all be forgetting about dementia? Forget what you know. What do you think people know and what should they forget?

**Mary Fridley (MF):** For me and Susan Massad, my Joy of Dementia partner of the last couple years, what we would love to help people forget – or at least create something new with – is what we and many other people have come to call the “tragedy narrative” of dementia. I think this touches on the work that we are all doing, and in our work, we have certainly been incredibly inspired by everyone on this call and many others.

Peter and others can speak much more coherently to how this narrative is related to the medical model, but from my vantage point, and in bringing out these performance-based workshops, I think it robs people of our creativity and perpetuates a myth that we aren't all creative people, that we aren't capable of creating new responses, new solutions, new ways of relating, new conversations and all kinds of new things in our lives.

Given that dementia is so totally over-identified as "a medical problem" and a problem located in the individual – this is something Susan has taught me a lot about – we talk a lot about the importance of creating what we've come to call the “dementia ensemble.” Dementia is not an issue just for the individual who has been diagnosed – it is socially, culturally expressed in a whole host of ways, so much so that I think our fears and understanding of dementia begin very early in life. I think it's forced upon us when a loved one or as we grow older, we start to forget and we start to worry and all of those things, but it's in our culture from day one.

We are working to impact on this by bringing people together to engage in creating something together, using play and improvisation and performance to begin to discover that, in fact, there are a whole host of ways to relate to dementia and the dementia experience that are more joyful, that are more playful, that are more humanizing, that are more relational. And we need to be able to do this together. We need to create a community, group, some kind of support, and environments in which we can take risks, do what we don't know how to do and challenge in practice what we've been told is or isn't possible with dementia.

**LH:** Thank you. It's a lot about possibilities is what you're saying.

**MF:** Yes, it's about really helping people see that there are possibilities and furthermore, they can be active creators of those possibilities.

**LH:** Thank you.

**Susanna Howard (SH):** We're all writers and actors who work with Living Words and the methodology that we use – the listen-out-loud methodology – means we always have to have the beginner's mind whenever we are working, whenever we're starting a project. It doesn't matter how many hundreds of individuals we've worked with, we have to go in with the complete open mind of, "We have no idea what is going to happen. We don't know anything." All we know is we're going to connect and we're going to do this methodology and we're going to see where it goes, but as soon as we start putting any sort of cognitive assumptions or beliefs of where things might head, then it's isn't going to work. So it's process driven and being fully with people.

We're starting to use our process with people who aren't living with the dementia as well and actually, it does extrapolate out to just how we all communicate with each other. But I wanted to talk about something that was really beautiful. Last week I was with someone that I've just started working with who is in late stage dementia and lives at home. We were doing a project where we're working with the person living with dementia and their partner, the person who's closest to them, who they live with. So each person will have a book of their experience working in the same way.

It was just our first meeting and I was in a room listening and communicating with the woman with whom I was working and it was so joyful for me because, for a moment, I overheard her husband and her daughter in the kitchen and they were listening in and saying, "Listen, listen. She's not asking her questions. She's not expecting an answer. But can you hear what they're saying?" And then they both said, "I think we're going to learn a lot from this" and "We don't do that, do we? We ask questions, we expect answers in the way we use language." That was a wonderful validation for the work, but also just hearing that openness to change after a lifelong communication and relationship where they have been talking in sentences and the usual structured ways and modes of communication and using language. So I think that touches on how we have to let go of knowing in order to connect and really hear each other.

**LH:** Susanna, given that you've mentioned your methodology at this point, maybe you could just say a little bit more about it. You weren't asking questions, so what were you doing with the woman?

**SH:** It's really simple and a really pure form of communication and art. We are with the person and repeating the words they may say, but it's about the relationship and then the words. But we're not taking it anywhere else. We're not alluding to understanding what the person's saying. We're not pretending that we understand – we are trying to sit in an equitable relationship with that person, human being to human being, and then using their sounds and words that to take the conversation further. It's a very nuanced process by being so pure and I'm really looking forward to finding ways to share how to work with people with more people across the world.

**LH:** Great. Thank you, Richard and Peter, what else should we forget about?

**Richard Coaten (RC):** I love that Susanna, thank you so much. It's a lovely segue into where I'm coming from and what I'd like to speak about, which is letting go of knowing in order to connect. As a dance movement psychotherapist, and I'm speaking to any dance movement psychotherapists out there who are listening, or any dancers working in health – this is something that hopefully you can relate to. But I want to build on Susanna's lovely thoughts about what she's doing in relation to the importance of the body and the importance of movements and dance and rhythm, and again, letting go of a sense of knowing in order to connect through rhythm, through movement, through dance, through song.

This is essentially what I do. In trying to increase the possibilities for a relationship and connection and finding way new ways to really forget what you think you know about dementia because if you are in that moment with somebody and you're thinking about stuff, "What should I do? What should I think now? What's happening here?", you're not being with that person in the way they need you to be. During this conversation, I'd like to open this up because it's a theme that I've been thinking and exploring a lot in relation to this question. Why should you forget what you know about dementia?

So I'm going to close with that sense of the importance of the movement, dance and song in order to let go of knowing, in order to connect and relate and celebrate who the person is now and who they're becoming. I've written in my papers about revealing a hidden humanity. I've struggled to put this into words because it's hard for dancers to put things into words. We're ephemeral. We work with the aesthetic, the esoteric and the really gutsy ways in which we communicate non-verbally. Dance helps reveal that which can't be expressed in any other way other than through the body, through movement, rhythm and the dance and music and song.

**Peter Whitehouse (PW):** Thank you Richard and everybody. To link what you all have said, what I would like us to forget about our work in dementia – or the dominant view of dementia – is the dehumanizing part. To me, the problem with the medical model is this notion that somehow people living with dementia are in a different category. I think everything we've said about working with people who have the label dementia is true of working with all human beings. I actually think that if we do forget some of these ways we've been thinking, we actually will re-humanize ourselves. I think the stakes are much higher than just our relationships with people with dementia. They're stakes for us as people and as communities and societies.

My journey began in the brain, if you will, as a physician. I still follow what's happening in the medical arena; in fact, this morning there was a big webinar from Canada about how we're going to find a more personalized approach to dementia through biomarkers. So they're still at it and they're still generating a lot of resources. I'm not saying we should forget all that because sometimes we have to not forget so we can remember not to make some of the same mistakes, but I moved on into being involved in individual care and then group care and then intergenerational schools where people with dementia go to school with younger folks, then into public health, which is where a lot of my energy is going. We need to prevent some of our cognitive challenges from emerging in the first place, and finally into the space that I share with you all, into the art space.

So I've worked with dance, I've worked with theater, I've worked with visual arts, and in my latest manifestation as a Hopkins MD PhD scientist, I have appeared as a metaphorical character asking big pictures about how we think about health in the world. That is as a tree doctor, not as a one who cuts off limbs of trees and fertilizes roots, but somebody who says to human beings, "We've got health rather badly wrong." By we, I largely mean the medical profession, but it's all our allies, including lay organizations who promote cure models over care models. What the world needs is a little bit more realistic expectations about what medicine can do and a whole lot more caring.

**LH:** So let me ask you all a question. It's a devil's advocate question that people who are listening might be thinking in one form or another. In business, they would say that what you're talking about is the human side, which businesses and corporations bring in consultants and experts to work on. I don't think you're talking about the human side of dementia in that same way because I don't think there is another side, but what do you say to people who say, "How can you possibly want care over cure?", to use Peter's words?

I know personally from the experience that all of you have is the practice is infinitely more joyful, more developmental, more intimate when you do the things that you are all talking about: involving the arts, the body, rhythm, song, play and more. When you're not taking words to mean what the dictionary says they mean, not looking for a coherent narrative, not looking for chronology, not judging people by how well they can tell a story that "makes sense." So back to my original thought – how do you respond to people who feel otherwise?

**SH:** First of all, I want to say to people listening that none of us are trying to put a silver lining on people's experience or saying "Hey, it's not that bad." What we're talking about is changing the way that we connect, communicate and view this experience. I was thinking a few different things having to do with who has value in our culture and who has value are people who have a future that we can see and we can imagine. But over the last 10 years, there's been a growing body of people in the earlier stages of dementia whose voices and experiences are being heard and it's been wonderful.

With some of our trustees, we've been looking at, "What is it that's stopping our work from being valued?" One of the many things we've realized is that, there is stigma within the dementia sector – never mind the larger world – around those in the late stages, which is who we're predominantly working with. This challenge needs to be unlocked and that's what we're hoping to, and aiming to, do. So we work really intimately with these people, and then we take their words out to the public. We have a single being released on Monday, which is the words of a man – a farmer – who is saying the most profound and beautiful things that really challenge the way we see humanity, how we believe that we can learn from each other.

So for me, it's shifting that value, but I do feel that people only really understand that when they experience our work. For example, the first show that I ever did to share the work was called "Crackpot," and that was because of something the daughter of a man that I worked with said at an event. She told the audience, "I've got to tell you, when I met Susanna, she said she was going to spend time with my dad, writing down his words about how he was feeling about life and present them in a book I could read with him." She then said, "Well I thought she was a

crackpot." And then she saw the book and started reading it with him. When he joined in, she said she just dropped the book and went to the loo because she felt ashamed that she believed that level of communication was beyond him.

So it's that experience. Every time we do a project, there's at least one relative who calls to say, "We've read the book, we've been with them. We can't believe that you've done this." I'm not saying this to brag or show off, or in any way minimize the experience, but sometimes someone from the outside going in and meeting a person can reengage and see a potential that people closer to that person might not be able to see. I really do just want to emphasize that I know everyone's experience with dementia is so important and I think that relatives across the world are doing absolutely amazing and incredible work in supporting relatives and parents living with dementia. So I'm not underestimating the challenges.

**MF:** When we developed *The Joy of Dementia* we added "You've got to be kidding!" because we knew it was a provocation and in fact it's been fairly provocative, mostly in a good way, although it also generates an enormous amount of anger and outrage that we would even dare to position joy and dementia in the same universe. And I've come to think that provocation is what is needed – and all of our work have provocative elements of that – because it's the only way to break through the dehumanizing ways people living dementia are related to. The "tragedy" set up is diminishing of everyone.

There's a wonderful improvisation artist, Karen Stobbe, who has inspired Susan and I. I don't know how many people listening are familiar with improv, but central to improv is "Yes, and" – which means you accept what someone is offering and you build with it. It's all about listening and about making your partner and the group succeed. What Karen has come to discover about how we relate to people living with dementia" – and I think it extends to most people as we grow older – is that we end up saying "No" to them all the time. "No, that's not right. No, what you're saying doesn't make sense. No, that's not what you should be doing. No, no, no, no, no."

Because it's come up in various workshops in some very touching ways, it finally dawned on me that it isn't any better to be the person who says, no, no, no, no, no, no all the time. That's not promoting her or his humanity. That's not promoting our cultural humanity. That's not offering a whole lot to build and grow with. So we do want to provoke, because in some profound sense, dementia is a provocation. I think dementia provokes the hell out of people. I think it shifts the foundation in a way that turns our world upside down. But what isn't seen so clearly is that, in doing that, it creates a fairly rich environment for growth and doing some new kinds of things and taking risks because you have to if you want to touch the person and create a relationship with the person they are becoming. I think we've got to provoke in order to touch each other and realize and to rediscover what it means to be human, especially in the moment in which we're living because it's getting harder and harder to be human, to be intimate, to touch people in some very simple but important ways.

**PH:** I think if I could just build on that and come back to your original question about cure and care, I don't like the aphorism that's used widely, "Here today, cure tomorrow" because it makes it seem like if we had more effective biological interventions, there would be no need or little need for caring. To me it's a matter of expectations, it's a matter of power and it's a matter of

money. In other words, I'm sure if somebody said we can cure malaria or tuberculosis or something that we have made some headway against but still have a long way to go, one would believe it based on an understanding of what medicine can contribute and what it can't. Dementia is essentially the result of everything that happens to your brain from probably before birth. I talk about lead poisoning all the time because it's a big problem and in the United States and other places and causes damage to the brain of a child that's going to affect them as an older person.

So this whole notion that we have limited resources and we have to figure out who we trust as agents in society to make a real difference for people. Doctors have lost some of that trust because they make promises. They say if we develop a pill, we're going to save money and they assume that we as a society will roll over and say, "You're the doctor, you're the experts. We listen to you. Here's some more money." Well, as Mary said, this is a different world. I say the greatest threat to the quality of life of people with dementia is global climate change. Look at Fukushima, look at the UK, look at all the floods, look at Katrina. There are things we should be doing that we're not doing in the world that will clearly demonstrate value to health and value to health for people with cognitive challenges.

**LH:** I agree, we are not doing very well. I was thinking of that even before you spoke Peter, about how it's not so much a function of getting older. People just don't remember all kind of things, including history – and it's a political issue that our collective memory is so terrible. To pick on people with dementia as those who don't know where they are is unfair because the rest of us human beings don't know where we are either.

**PH:** Danny George and I have a book coming out called *Brain Health in an Unhealthy Society* and it's basically about what you said. It's the politics, it's the economics that are making us sick. There are a few people in the world who seem to be doing okay, but they're the people who are planning to send a rocket to another planet because they know that their activities have totally fouled up the planet. So they have a plan, which is not a very good plan for them or for us, but as a group, we've got to rise up and see neo-liberalism, see the challenges of democracy as part of the bigger picture of brain health.

**RC:** Peter, I love that really wide scope, that broad brush stroke of the context in which our work is happening and I'd like to go to the other end, the nitty-gritty detail and for myself, talk more about why we should forget what we know about dementia. I came up with some thoughts and the first one was around the origin of the word dementia, which comes from the Latin demenses, "de" meaning "out of" and "menses" referring to mind. In other words, out of one's mind. It's essentially a misnomer because in order to know what it means to be out of one's mind, we have logically to be able to define what it is to be in one's mind, and this is successfully alluded to the greatest philosophers. Thus, dementia ends up as a term loaded with stigma, fear and myth about something Alois Alzheimer and his early researchers considered a natural part of the aging process. In other words, the term dementia is unfit for this purpose and should be forgotten.

Secondly, much of what we've assimilated in society generally about dementia is unquestioned, unthought through and based on considerable ignorance and assumption. For me initially, it was Professor Tom Kittwood who inspired me hugely and opened my eyes and heart to a different vision. As he wrote in the last page of his pioneering book, *Dementia Reconsidered*, back in

1987, "Above all else, the reconsideration of dementia invites us to a fresh understanding of what it is to be a person. The prevailing emphasis on individuality and autonomy is radically called into question and our true interdependence comes to light." It's as relevant now as it was then.

So going forward, this fresh understanding of what it is to be a person, this great mystery about the human condition is being shown us by some of the most vulnerable people in society, but only if we can still ourselves listen and attend in ways that require us. If we can get our own assumptions about what we think we know, if we can get our egos out of the way, and if we can be fully embodied, fully present and fully relational, then if we are lucky, its mysteries may just reveal themselves in all their beauty – and I use the word beauty deliberately.

As my dancer colleague and friend Miranda Tufnell says in the program of a dance piece she has performed, "Breath signals our birth and our passage from this world. As we listen to the tidal interchange of breath in the body, memories and dreams rise to the surface of awareness, making visible our uniquely personal sense of being alive." My uniquely personal sense of being alive does not go away in dementia. What goes away is the confidence and skills that we all need to go on relating to and learning from aspects of ourselves that get in the way of our being with people with memory problems as they need us to be. Michael Verde from the Memory Bridge Project talks about this very beautifully in *Love, Loss and Laughter*, a book by sociologist Cathy Greenblatt, who through her amazing photography is challenging the stigma of dementia.

On page 88, Michael writes, "One way to make the gone reappear is for scientists to find a cure for their disappearance. Another way for the gone to reappear is for our egos to disappear when we communicate with people with dementia. Here is a simple way we can do this, intellectually simple, but emotionally very difficult. The next time you communicate with someone who is not at her or his cognitive best, remind yourself of this. This interaction is not about me. This interaction is about someone who is seeking connections on terms that may not advance the interests or needs of my ego. I am going to go where your needs are taking you. I am going to be with you in that place wherever and however it is. I am going to let my ego disappear now. I am going to love you in your image instead of trying to recreate you in mine."

**LH:** I think it's a beautiful quote that resonates with what we're discussing. But Mary, I think that the dementia ensemble as a methodology and a unit, if you will, suggests that it's perhaps a little more relationally creative than giving up your ego and going where that person is. I understand what the language being used – and I think the creating something new out of who you both are right now is a little bit different from the sentiment of that beautiful quote.

**MF:** I agree so I hope you'll let me babble for a bit. I remember when my mom was going through late stage dementia and I read a very helpful list of things you're supposed to do with people with dementia. You're supposed to go on a journey with them. You don't negate or argue with them. You do all the things that I think we should be doing as decent human things in life...

**LH:** ...with anybody.

**MF:** With anybody. However, then I thought, "No one knows how to do this." We live in a culture where we're always negating and arguing with people. It's as common as breathing. We



don't particularly go on journeys with people. We're not terribly curious. One of the people living with dementia who Susan and I have worked with recently said that he thought the field needed more wisdom and less education. I would add – and I think he would agree – that we need more creativity and less education. What he was saying is there's a ton of education out there and no one knows how to use it. We end up feeling lost, so for us, creating the dementia ensemble is how we can get “unlost.”

We pay a lot of attention to really helping people – and performance and improvisation are very valuable in doing this – is helping people create rather than know. We work with them on discovering how to create with all the things that are going on in a way that's very specific and touching to their lives and the actual relationship they have to the person or people that you want to be who are in your life. All of this is something that's going to have to be collectively created. And in doing this, people are able to say, "Oh, okay, now I can see a glimmer of what else is possible" if we do it together.

This may sound strange, but I think the most valuable thing about our workshops is that we give people a lot of room to play in whatever ways that looks like for them. We especially want adults to have the experience of playfully creating with strangers. We bring together as broad and diverse a group as possible, including people living with dementia, caregivers, medical professionals, concerned citizens, whoever wants to be in the room. One, because they don't come together very often to have these kinds of conversations, but two, they never play together. They never get to try out new things together.

So to come back to your question, yes. I think that we're going to have to create what that journey is. And we're going to have to find ways to empower people to create them just in regular old life ways. It's a challenge and I think that's why people respond and are so impacted on by the work because I think they go, "Oh, I can do this. We can do this. There actually is a “we” who did some different things together. We came alive." That's very powerful because it's not the experience we have every day.

**LH:** What you're saying is helping me to realize that giving up our egos is giving up this absolute commitment and glorification and obsession with the cognitive and the rational.

**PW:** I work in intergenerational spaces and I do think one of the world's problems is that kids know how to play. Older adults, elders can get into that playful space and that adults have problems with that. But although I like the word creativity, I would like to defend something about wising up or wisdom because I think the other side of wisdom is a recognition of limits, is a sense of humility. I think wisdom is more than cognitive and it gets into some integration and balance, which we're trying to find in this process. I just thought of something, if when we refer to people with dementia as PWDs, as they sometimes give us permission to do, I wonder if we started, it doesn't rhyme, but I wonder if we call the rest everybody, PWH, people with humility or people with humanness.

Because I think every time you put the word PWD, every time we talk about doing something for somebody with a dementia, we need to recognize that in practically every space you've got people with different cognitive abilities, so let's just put in that space a person with humanness. I

think that we're talking about dementia friendly and age friendly communities. There are several books, one of which I'm going to quote or mention, *The Compassionate Civilization*, that says, "It's not just our individual humanness. It's what can we learn from enhancing the role of the arts in our humanity and in our communities, in our very society fabric of society." Because it seems to me that this is another example of why it's bigger than just our natural desire to help those of us who are addressing the challenges. I'm going to use the word suffering because look, I'm enough of an amateur Buddhist to know that suffering is in the heart of many of us as we live, but there are different forms of suffering and we address suffering in community.

**SH:** I just wanted to respond to the quote that Richard cited and I agree it's beautiful. I have concern though that it does go into the realm of otherness, othering, very much like "I will do this for this person." I can remember 11 years ago applying for some money and I was sent the feedback form which said, "There is no evidence to prove that anything like this works. It seems like this woman is nothing other than a do-gooder." So the do-gooding aspect I think is really is a stigma and a challenge. Certainly in the way that we work, which is always with a sense of inquiry, we're constantly trying to look at that equity, that togetherness, that going into that space together. Not like, "Here I am, casting off my ego." I'm not suggesting they're saying that, but it can be misinterpreted in that way.

The people we're meeting are completely and utterly who they are right now. If we can be who we are right now and drop into that place of humanity, that shared communication, it could be just like, "Here we are together, now let's just see where this leads." So I know it's a slight thing, but I think it also connects to what Mary was saying, and I like the idea of there being a fluidity; of enabling and supporting ourselves and everyone to be in a space of fluidity. I would suggest this is a positive about the world in this moment – that the fluidity of communication, the fluidity of labeling that is beginning to occur, the fluidity of what we expect of ourselves can really lead to something.

And then the final thing I wanted to say was just I really loved Richard talking about rhythm. It was so lovely and it made me think about a woman who was speaking to a book festival in the UK by Skype. She was talking about how she connects to a sense of rhythm in language, then the words just come and fill it. She has the rhythm and then she connects to the feelings and then the words come. It struck me that it's so connected to how we work with people with advanced dementia and it made me think of this woman who I worked with years ago who said, "More and more to me, God is just the rhythm of the world." I thought that that beautifully brings perhaps those elements together maybe. Thank you.

**LH:** Thank you. Let's open it up and hear what people have to say; their comments, their questions for our guests. I see a question in the comments section that asks, "For Mary, what is an example of how you would teach a person with dementia in the third stage and their family member to play?" So Mary can answer and then other people may have other things to say.

**MF:** I was thinking about a workshop that we did in Boston a couple of months ago where we had people living with dementia in the workshop, although we didn't know that and we don't generally know that unless they self-identify. All of them were involved in the exercises and the performance games that we were doing, but in one of them – an introduction game in which you

need to introduce yourself as your partner – it was clear one of them was having difficult remembering what his partner had said.

In one of the most lovely performances I've ever seen, his partner began to speak for him as him introducing her. She very gently started to say, "I'm Ann, I have three kids, I'm married to Mike," and so on. She went on until he was able to continue the introduction, which he then did. For me, that's playing. For me playing is moving this much [makes small space between thumb and finger] outside their comfort zone to do something we might not ordinarily do. Or it could be responding with curiosity to a person with dementia saying, "My sister Judy came yesterday to visit" – and Judy has been dead for many years, with "Tell me more about your sister."

But I think mostly what I would say is make sure you have the support to be playful, to take some risks. I'm really trying to be careful about not doing a cookie-cutter, "Oh, if you do this, then that will happen." I think it really has everything to do with the relationship to this person living with dementia. What are they offering? Where do you want to go with it? What can you do? And this is where I've been enormously moved by Susanna and Richard's work. Can you create a poem? Can you dance? It's exploring other possibilities and looking at where you can go together.

**RC:** Can I just say to that lovely question, it's a great question. Just put some music on and dance and see where you go.

**PW:** I would say the same thing and add two more things – make sure you are ready to play, and also if you've got a child hanging around, be sure to get the child involved.

**MF:** I also want to be say that's it's not easy for adults to play. It's not comfortable and we don't do it naturally. So I think we can be more comfortable, to Susanna's point, with focusing all our attention on the person living with dementia or whoever we're taking care of. Thus, it's important to get the support you need to grow your capacity to play and to be with someone in whatever ways that has to look. I don't want to make it seem like play is easy so that if someone tries and finds it difficult that they don't feel like, "Oh great, I've failed at that too. I can't do that right." So it's important to create a playful environment, which means you've got to find some playful people.

**SH:** There's something about reveling in the absurdity, noticing things, not covering things up and going with the things that in regular life we might want to avoid – in going into those places, we can connect more humanly.

**PW:** Can I just say two things though? One thing in general with people who have short-term memory problems is also go back to how they used to play when they were younger, because quite frequently, that will tap into some really important things. And second, I guess I'm an unnatural person because I think play is natural or at least it could be naturalized. I think we've done a lot in society to denature play and so I'm not objecting too strongly but I think we are a playful species as well. I think it is essential to humanity, to being human.

**MF:** I agree, and that's why I love you Peter. You're unnatural. And I'm glad we're all helping

other people learn to be more and more unnatural because it's important.

**LH:** One question you can ask yourself on the way to becoming more playful as an unnatural and natural thing is, does it matter? What hinges on, "Aunt Mary came to see me yesterday," and Aunt Mary happens to be dead? Does anything hinge on what you say next?

**SH:** I would say it does. In the UK, there is a lot of talk about this new term, "therapeutic lying." What it's meant is that in the last couple of years in care homes, I've noticed that at the end of the workshop we were showing staff the poetry books and I remember a member of the staff saying, "What a relief. You've taught us how to communicate in this way because we'd been told we could lie." And they didn't want to lie. I'm concerned about that because I feel that if we respond and we connect with emotions, then we don't engage in lying. For example, if someone is seeing something that "isn't there," I'm not going to pretend that I can see it as well. I'm going to say, "I can't see that, but I can see that it's making you feel whatever is." For me, this is really crucial to actually our humanity and the ethics associated with how we have equitable relationships with each other.

**LH:** I guess what I was really asking is does anything hinge on these so-called truth based responses?

**MF:** At a workshop we did in New Hampshire, a very lovely woman talked about her difficulty responding to her mom, who is living with dementia, insisted that the same cloud appeared outside her window every day at 4pm. As she explained, "I called upon every scientific fact and knowledge that I could come up with to tell her that couldn't be so." So I asked her – with curiosity, not critically – why it was important to make sure her mom knew that. She said, "Honestly, because I couldn't bear to see her that way. I wanted her to be the person she was." I think this is a genuine source of pain for people, though I also think it has as much to do with the care partner as the person with dementia. There is a real yearning for wanting that person "back". I think it's an honest human feeling, though I think it can be problematic if you project your experience onto the person living with dementia because they're not having the same experience. Her mom wasn't worried that there was no scientific evidence that the cloud couldn't have appeared. But I do think her daughter genuinely wanted something for her mother, and that's painful.

**LH:** I know we have other questions, so let's move on to Griffin Smith.

**Griffin Smith:** Hi, I live in Atlanta and I want to thank everybody. I'm finding this conversation utterly fascinating. Lois, I'm very interested in social therapy, which is something that I'm learning more and more about. I'm also a student of and very interested in analysis, and a lot of the concepts I think that you guys are touching on reminds me of different concepts that have emerged through analysis that I think have a lot of bearing to what you were saying, particularly the idea of creating a space for a person to be natural, to create that space for them to play. It reminds me a lot of what Donald Winnicott talked about with the holding environment, creating a space for a person to experience themselves and experience what's happening without us saying no, without us putting a chop on at the word, to begin the work with that.

Also, to jump to another part of the conversation that I really enjoyed. Richard, when you gave the quote about the ego and not imposing your own ego into someone else's, there was kind of a back and forth about that. I think that can be a really challenging thing to wrap our heads around, this idea of truly letting go and being with someone else because my sense is that it's not totally possible. Rather than fully letting go of our ego, which is to some extent impossible, well what we could perhaps expect to do is create what Jessica Benjamin referred to as the third space. It's the synthesis of you and that other person creating something new from your interactions. It's a new type of experience where in a sense, both you and the person have changed to some degree.

**LH:** Thanks for your comments and references to analysis. Very, very interesting. Anyone want to comment on that or should we move on to the next one?

**RC:** I am a psychotherapist and I did have six or seven years of Jungian analysis and that analysis contributed to my developing doctoral studies in dance movement, psychotherapy and dementia. The idea of the dance therapy session acting as a holding space is a really important one. Thank you, Griffin for mentioning that. I also like the idea of creating a third space, a new type of experience, a relational space. Recently in some of my workshops, I've been calling it dancing the in between – it's the space that we create between each other and you're right, it's extremely difficult to get our egos out of the way, but my sense is that this is what we're aiming for in our play. We're aiming for a state of flow. We're aiming for movement. We're aiming for rhythm. We're aiming for ways we can re-stimulate and reinvigorate our uniqueness as human beings – all of us, not just people with memory problems.

**LH:** We have Nancy next.

**Nancy:** Hi everyone. I mostly want to say what a wonderful mostly want to say how wonderful this discussion is and how beautiful. I just got back home from seeing my mother who has Alzheimer's, and my father, both of whom are 91. There's so much richness in this discussion and I just want to let you know how much I appreciate that. I felt like my mother was much more alive in her dementia than my dad is able to be. This discussion has just made me appreciate the depth of this issue and the ego, the centrality of the ego and the individualism and I loved what everyone was saying, but I just did want to call out what Mary saying about dementia being a provocation to us and to humanity. I love that and I love you all. Thank you for doing this.

**PH:** I think the question provoked me to share an expression, “If you see one person with the label Alzheimer's, you've seen one person with the label Alzheimer's.” One of the big problems – and the experts are lying to us about this – is that Alzheimer's is not one thing. It's a variety of different conditions that will affect your dad or your mom or whoever in a variety of ways. That's the nice thing about being a geriatrician. Human beings are really variable and when they get older, they get even more variable. If you like the diversity, go for it. But this idea that we homogenize people into one category is part of the problem.

**LH:** I'm going to read Andrew Stewart's question: I'm interested in looking at this topic from a structural level. I recently read an article by Lynn Sandberg, a professor at Stockholm University, who's calling for a critical dementia studies network. She says, "How often is discrimination against people with dementia cast as stigma and a matter of managing

interpersonal dynamics, rather than seen as a question of structural oppression? How often is coping with dementia deemed a matter of character and a question of resilience in the face of adversity rather than linked to processes of social exclusion and political disempowerment?"

**PW:** The idea that a lot of our human problems are systems problems and societal problems and our problems with our relationship to nature is important, so I think a critical lens is important. If we see things through a critical lens, we'll see things both bigger and smaller at the same time.

**LH:** This is from Meika: I'm interested in the discourse around lying to people with dementia. In other words, going along with their erroneous ideas of reality. It's interesting that responding in a human, authentic, deeply relational way is considered dishonest, whereas it's somehow more honest the cling to a certain conception of truth at the expense of human connection. I was exposed to this idea in learning about the reality orientation approach as opposed to validation therapy in my training as an occupational therapist.

**SH:** It was Toby Williamson with the mental health foundation for older adults who spent a couple of years doing research into truth and notions of truth and lying. There were lots of really interesting people involved in that. We're able to download the research and I would encourage people to take a look at that.

**MF:** I know we have to stop, but I have generally experienced honesty as relational and truth to be more authoritarian. So I'm a big believer in honesty and don't have a lot of use for truth with a big T in any human relationship.

**RC:** I work with this a lot on an everyday basis on an old age psychiatric ward in the National Health Service in the UK. And my question to myself when I'm hearing this is how can I make a connection? How can I enable this understanding or this image or this symbol to lead to a sense that the person can be present with me and I can be present with them and we can see where we can go with it? Because being very direct with somebody and saying no when they're wanting their mother or their father has an impact. If you say, "No, they're not alive. They're dead," it leads to another conversation about, "What? They're dead? How do you know they're dead? What? They're not dead. I saw them yesterday." By rejecting that notion, you end up traveling somewhere else, but in that traveling, you might not be supporting the person's wellbeing. You might be causing distress. So one has to think about that ethically.

**LH:** I've so many things I wanted to say, including questioning how we understand almost everything, including words like connection that resonate for me and everybody else. What are the assumptions about how we are together as human beings to say and to believe and to practice making a connection? Does that imply that we aren't connected? Anyway, I could take every single word that we were using and play with the assumptions that underlie them. One of the things I mean by play is playing with words and our assumptions about them – and it is wonderfully growthful and fun to be able to do that. So thank you everybody for a wonderful, wonderful conversation. Keep up the great work, and audience, please contact us and learn more. Thank you.