Caring for the Deeply Forgetful

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Mike Egnor:

Welcome to Mind Matters News. This is Dr. Michael Egnor, and I have the pleasure today of speaking with my friend and colleague, Dr. Stephen Post. Stephen is an internationally recognized authority on Alzheimer's disease and other disorders of memory, and he has written a wonderful book recently, the Moral Challenge of Alzheimer's Disease: Ethical Issues from Diagnosis to Dying, and he is extremely interested in the ethical and philosophical issues related to the care of deeply forgetful people. Stephen's a graduate of the Divinity School at the University of Chicago, and he has extensive training in clinical pastoral care, and he is the founding director of the Center for Medical Humanities, Compassionate Care and Bioethics here at Stony Brook. And Stephen and I have known each other for many years. We've both taught in the ethics course here for medical students, and Stephen is a very good friend. So Stephen, welcome and it's a delight to speak with you on My Matters News.

Stephen Post:

Thank you for having me, Michael. I'm really grateful and I'm looking forward to an exciting conversation

Mike Egnor:

And me as well. So to begin, your new book, Dignity for Deeply Forgetful People, why did you use that title and what do you mean by deeply forgetful people?

Stephen Post:

Well, that's a fabulous question to begin with because the title doesn't quite say it all, but it's close. I've been working with deeply forgetful people and their caregivers since I went out to Case Medical School in 1988, and I have never felt comfortable with the term dementia, at least in a public sense, because it's a term of decline, dementia from a former mental state, and it very easily leads to negative metaphors like husk, shell, gone, absent, even dead, vegetable and the like.

That's very unfortunate because it, first of all, leads us to think about them being so categorically different from us. So it's them versus us type thing, but also, it blinds us to noticing, and noticing is a very important word, noticing the hints and the expressions, which are sometimes spontaneous and sometimes elicited by music or nature or old factory type phenomena and apple pie. People come back into themselves to varying degrees, and our job is to notice and to embrace that and to stimulate it and so that we can realize that grandma is still there. And it may be a bit mysterious for us, but deeply forgetful is much more a concept of continuity. We all have our forgetful moments, I'm sure I do out in the parking lot when I'm looking for my car desperately and wondering if I even drove to work today.

But sure, deeply forgetful, it's almost mystical and it's intonations suggesting that deep forgetfulness frees us from some of the chronological pressures running around from point A to point B to point C, and always being so worried about hyper-cognitive values, linear rationality. I talk a lot about symbolic rationality, which is always there with these individuals and can be stimulated through many, many different devices. So I'm wanting to get away from the word dementia.

Mike Egnor:

What do you mean by symbolic rationality? That sounds fascinating.

Stephen Post:

Well, that's an important question. I spent 20 years in Cleveland. I knew a fellow who had severe Alzheimer's disease. He always clutched his cowboy hat even to his last day of life. And it was as though he knew that somehow his identity was connected with that symbolic object. And as it turns out, I learned from his daughter, he had worked in the steel mills on the west side of the Cuyahoga River all his life, and he always dressed country and western. So somehow he knew that that symbol was important to who he was. You can take de Kooning, the great abstract expressionist artist, he was diagnosed at Cornell Weill New York Hospital, and for 14 years he had dementia, most likely of the Alzheimer's type. For 13 and a half of those years, he would paint, he would be in a loft in Greenwich Village. He was accompanied by an assistant. He always wanted to wear the same pair of painters dungarees, and they had several of them splattered with paint so they could wash them and so forth. But he knew that that was who he was.

And sporadically he would rise up, take his paintbrush and dip it in the acrylic paint. Then he would go up to the easel and he would paint. And his early painting when he was fully "intact" was so anxious, and he was really one of the most incredibly forceful painters of the age of anxiety, but as he became more deeply forgetful, he became more quiescent. He painted things that looked a lot more like Georgia O'Keeffe. The colors brightened up and I think he came into himself, believe it or not, artistically later on. Of course, some of the critics said, "Well, he was a husk, a shell of his former self." But the one I liked said, "Wait a minute. He had Alzheimer's for 14 years and for 13 and a half of those years, he knew he was an artist and he painted." And there was an posthumous exhibit of his work at the Metropolitan.

So I think we always have to recognize the continuing presence of symbolic identification. I tell the story in the book of a fellow I met at a nursing home in Chardon, Ohio, and it was a special care unit. Joe Foley, the famous neurologist who was my mentor, we went into Jim's room and we read his little biosketch on his wall and we knew he had a couple of sons. And the nurse guided me out with Joe to meet Jim, and I took Jim to a table. We sat down and I said, "Jim, how are your sons?" And he couldn't respond. But then I said, "How's Davy and how's Luke?" And by using language to cue him and prompt him, he actually lit up a bit. He wasn't conversant, but he lit up.

And then he had a white twig in his hand, talk about symbols, a white twig in his hand. It was painted white and the ends were blunted and wasn't harmful in any way. And he put it in my hands and he smiled this effusive smile, and if love was electric, that place would've been on fire, Mike. And then he said to me three words. He said, "God is love." And it turns out I asked the nurse that he grew up on a farm in north-eastern Ohio. His father was a Christian and they went to church and his father loved him very much, and Jim associated tender loving care with that period in his life to which he had gone back. And that white stick was a symbol for the kindling, the nurse said. And his father had always him go out and get the kindling in the morning as he was growing up. And so that was his way of reconnecting with his loving dad.

Mike Egnor:

Very interesting, fascinating. I'm also fascinated by the reference to de Kooning, to the artist, and that artistic ability may be not only retained but perhaps enhanced in people who become deeply forgetful. I know that there are people with autism who have remarkable artistic abilities. Do you see a connection between the two scenarios?

Stephen Post:

Yeah, well, I have a lot of interest in autism, and we did the Stony Brook guidelines on the care of people with autism and published it in about about 10 years ago, but most definitely. People with dementia, there are case studies of this, which are across the literature, individuals who have never been artistic before, who have never been skilled at painting or drawing, a certain small subset, there are probably 15 to 20 cases in the neurological literature, have become artistically disinhibited, and suddenly they're doing images that are reminiscent of say, the Spanish caves. And so there's something in there that they're connecting with, and it's quite remarkable.

I knew a guy who would come into the Elder Healthcare Center in the mornings. It was an art support group, and he had his black crayon and the white paper board, and he would just very chaotically put down anything that came to him. And we assumed it had no meaning whatsoever. But always down the middle of these pages, he would put two lines parallel. And it was quite remarkable because he did this day after day after day. Of course, if we asked him in the morning, "What is that line?" He couldn't correspond at all. He couldn't speak. He was roughly mute and that was the deal.

But one morning we asked him, and he was particularly lucid that morning because we do talk a lot about paradoxical lucidity in these populations, and I said, "So what is this? It looks like a tree trunk." He said, "No, it's a road so my daughter can find her way to my home." So there was more purpose and intentionality in that world of symbolism that he was connecting with.

There was a famous New Testament exegete and a friend of mine named Leander Keck at Yale Divinity School for many years, and his wife, Janet, succumbed to probable Alzheimer's. Eventually she was just being escorted somewhat around the Yale Divinity School campus, but she wasn't able to communicate by speech and seemed to be quite lost most of the time. But when she went to the Yale Chapel, which she had done for all those years on a Sunday morning, she would brighten up like a new day. She would get somatic when the hymns were sung, she would chime in with the hymns and sing them oftentimes all the way through to the end. She would brighten up when the light shined through the windows, and she would very easily recite classic prayers, the Lord's Prayer and so forth. And she became symbolically alive.

And then after those experiences in that symbolic community, she could actually converse, not for a long time, but she could converse for say, five to 10 minutes and actually respond to people so long as they use language intelligently. Don't do open-ended questions. Don't say, "What did you have for breakfast? Did you have ham and eggs or Post Toasties?" That's closed ended. So you're always giving people language to use, and so they're not stressed out about trying to recollect some particular word, but she became herself for a period of time. It didn't last long, but it was incredibly stimulating for everybody who knew her and for her husband because they realized Janet Keck isn't gone, she's not absent, she's not a husk, she's not expendable, she's not subhuman. She actually has moral consider ability just like anybody does, but she's deeply forgetful.

Mike Egnor:

It's very interesting that back in the 19th century, there were several philosophers who suggested that the relationship between the mind and the brain is not that the brain generates the mind, but rather that the brain focuses the mind. It was a dualist perspective, that the mind has a very independent existence from the brain, and the brain enables the mind to function appropriately in nature and to meet our biological needs. And that there are situations where impairment of the brain can actually enhance the way the mind works, which I find incredibly fascinating. When you refer to paradoxical lucidity, what do you mean by that?

Stephen Post:

Well, I'm talking about the roughly 80% of caregivers who self-report moments of absolutely surprising lucidity. They assumed that their loved one was gone, absent, a husk, a shell, incapable of being present in any significant sense. And yet, lo and behold, that individual either is totally spontaneously or sometimes prompted by symbols, by personalized music, will actually come back into themselves. Music is the most effective in this area. There's a national movement called Music and Memory, and one of our medical students, and myself, Angela Lowe, did a study of personalized music using an iPod here at the VA nursing home on campus. And we were in a unit where there were probably 30 individuals. They were all sitting in chairs. None of them were speaking. They were ambulatory to some degree. And we took them into the activities room. These were all, of course, veterans and the big television on the wall with the furling flag in the wind, the music was God bless America.

And I will tell you that 80% of these people actually stood up and sang a few lines, if not a whole verse, if not the whole song of God bless America. And when they did that, they became somatically active. They were effectively present. They were capable of expressing all kinds of emotion. There wasn't that distant flat look that you generally associate with deeply forgetful people. They were more there than not there. And then the question is, as you ask it, does that mean that they really are there or are these moments of, call it rementia, there's a word for you, rementia, although they're fleeting, are they simply the fragmented, sporadic firings of certain neurological connections that are really meaningless and empty? That would be your materialist view, that mind is in fact matter. And when the brain goes, the mind goes and all self-identity is gone.

And then we might as well put these individuals in Auschwitz. And, of course, I can talk about what happened to these individuals in Nazi Germany when they were defined as life unworthy of life, as useless eaters and so forth. And many of them did wind up being killed in the hypothermia experiments. But the interesting thing is that if you take a different metaphysical view, the one that I learned from the great neurologist, Sir John Eccles, who was at the University of Chicago, we briefly overlapped there, and he got the Nobel Prize for figuring out most of the basics of synaptic communication in brain cells.

And I'm just going to quote something from him. It's one of my favorite quotes. It's from his book, the Evolution of the Brain. It's just two lines. I maintain that the human mystery is incredibly demeaned by scientific reductionism with its claim in promissory materialism to account eventually for all of the spiritual world in terms of patterns of neuronal activity. This belief must be classed as a superstition. We have to recognize that we are spiritual beings with souls existing in a spiritual world, as well as material beings with bodies and brains existing in a material world. And that actually is my view of it.

Mike Egnor:

It's very interesting that there were a number of classical neuroscientists, Eccles, Sherrington, Penfield, Benjamin Libet, who were doing this and who really embraced this viewpoint that the mind and the spirit have an existence that's separate from the brain and the body. But you see less of that nowadays among neuroscientists. Why do you think there's been such a materialist turn in neuroscience?

Stephen Post:

Well, you do see less of it. I think Sir John Eccles was writing in the 1980s, the 1970s, 1990s to some degree. But you're so correct. There are all these individuals of his era, Sherrington, Penfield, Edgar Adrian, these individuals were taken very seriously. And of course, if you go back a little further Henri Bergson in Mind and Memory had all these kinds of ideas. William James had these sorts of ideas. So the materialism of it all is a relatively Johnny come lately approach. And the argument, I think, is that it actually is somewhat implausible. It's implausible to think that somehow this rementia, this experience

of rementia, this return of a personal identity, that could be explained purely in terms of some small segment of brain tissue, I think it's unlikely.

So one of my great friends, a pastor in Cleveland, he was from Detroit originally. He's a very famous guy. I can't give you his name, but his sister died of Alzheimer's about a year ago. And I was talking with him on the cell phone and I said, "Pastor, are you with her now?" He was with her the last couple of weeks of her life. And he said, "Yes." And I said, "So what is her state? Is she still there?" And he said, "Yes, I believe she is still here with us, although she may be down at the Amtrak station or with one foot already settled on that blessed train for glory." So what he was saying was that in a way, she was liberated from chronological times. She was liberated from space and place, and she was already moving forward, he felt, to something that is a mystery, but is very beautiful.

Mike Egnor:

It's absolutely fascinating. And what's also fascinating is how so many different lines of evidence, evidence in clinical medicine, evidence in the study of deeply forgetful people, evidence in exceptional recent neuroscience research, all point to the same basic insight, that the mind has existence that is to some degree separate from the brain.

Stephen Post:

I think that the definitive statement on this is by the great Princeton philosopher considered really one of the greatest living philosophers of the 20th and the 21st century, Thomas Nagel and Thomas Nagel was a philosopher of mine. He hung out with all the great neuroscientists of his day and he still does. And his book Mind and Cosmos takes the view that the mind is part of some much larger reality. He talks about one mind. Of course, Schrödinger talked about the one or the original mind, there's only one mind in the universe. That was Nagel's point of view too. And it's actually my point of view as well.

I think that we all have the gift of the mind. We are stewards of the mind. The mind is equivalent with spirit to me. And it's something that we don't fully understand. But it's very difficult to, in any way, rationally argue that mind can come from matter. I know there are probably a dozen pretty good people who have theories about how this can happen and they compete for funding, and they're going to figure out how consciousness in mind comes from just inert matter. But I just think that's not going to happen.

Mike Egnor:

Yeah. I think one of the fundamental difficulties with explaining how mind can come from matter is that our modern definition of matter really derives from Cartesian metaphysics from Descartes and Descartes defined matter as stuff that's extended in space, as ponderous stuff, stuff that has weight and volume. And of course, things that are defined as having weight and volume are implicitly defined as lacking mental attributes, is that basically Descartes stripped mental attributes from physical things and put them in the soul in a separate substance. So materialists work really in that same metaphysical framework, that they strip mental things from physical things, but then they're stuck with a problem of explaining how mental things can arise from physical things, which they can't do. So it's a problem of their own creating, and it's a result, I think, of materialist metaphysics.

Stephen Post:

I think that's correct. And I would say further that one time a reporter asked Bertrand Russell if he thought there was any such thing as human dignity.

Mike Egnor:

Right.

Stephen Post:

Now, Bertrand Russell was a devoted materialist, and he said, and I'm quoting accurately here, he said, "No, how can there be? We are simply glorified pond scum." Now, if you take that view, then you're right back to 1939 in Munich, when they took 70,000 individuals out of asylums, about half of them, the historian Benno Müller-Hill argues, about half of them had dementia, senile dementia. They didn't use the word Alzheimer's at the time, and about half of them were cognitively, developmentally disabled. And they felt that these individuals had absolutely no moral value. They were not members of the human family. There was nothing there to be concerned about. So they put them out at night in small groups to lie down in the cold snow. They would pack them in ice. They would leave them in freezing water for hours, until then they would bring them in back into the asylum, and they would warm them up at different temperatures in different mediums, sometimes water, sometimes hot air blowing on them.

And, of course, this is the T4 project, the Tiergartenstrasse Four project, and the German scientists said they were doing this because they wanted to know at what point would it really become totally futile to send rescue teams into the cold waters of the North Atlantic, first down submarines or whatever. Of course, that was hideous and no justification for anything like that. But at any rate, after a year and a half, the Germans, people themselves, reacted to this because these people who were deeply forgetful, they weren't of this typically discriminated against groups. They weren't Jews, they weren't Polish Catholics, they weren't gays or whatever, and they were, if you will, perfectly blue-blooded areas.

And so the German people reacted against this. And the same two principal investigators who handled the Tiergartenstrasse Four project went right to the death camps of Dachau and also Auschwitz, and they began perpetrating or inflicting the hypothermia research on these different discriminated against populations. So I think it's always worth remembering that medicine got to its lowest point ethically ever. We're talking about the annihilation of people simply because they're having problems with their memory, they were annihilated first among individuals with these cognitive disabilities, what we might call they're being differently abled nowadays.

Mike Egnor:

Oh, that's absolutely fascinating, Steve. Maybe we should wrap up the segment. And this has been a fascinating discussion with my colleague and friend Stephen Post from Stony Brook. And thank you all for listening and please join us in future for more discussions. This is Dr. Michael Egnor from Mind Matters News. Thank you.

Announcer:

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