Caring for the Deeply Forgetful: An Interview with Dr. Stephen Post

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Announcer:

Greetings, how can we best compassionately relate to those suffering from Alzheimer's disease? Is there more to the mind than just the brain? Dr. Stephen Post, author of the book, Dignity for Deeply Forgetful People speaks with neurosurgeon, Michael Egnor, about memory, consciousness, and medical ethics today on Mind Matters News.

Michael Egnor:

Welcome to Mind Matters News. This is Dr. Michael Egnor. 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 is 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 Mind Matters News.

Stephen Post:

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

Michael 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 a 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 olfactory type phenomenon, 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 in its 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 hypercognitive 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.

Michael 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 painter's 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 and I, who was my mentor, we went into Jim's room and we read his little bio sketch 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 Davey 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 symbol, that white stick was a symbol for the kindling the nurse said. And his father had always had 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.

Michael 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 10 years ago. But most definitely people with dementia who have... 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. 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. 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 close-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 considerability just like anybody does, but she's deeply forgetful.

Michael 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. That is that 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 Lo, 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. 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. 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 affectively present, they were capable of expressing all kinds of emotion that wasn't that sort of 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 pretty much, 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.

Michael Egnor:

It's very interesting that there were a number of classical neuroscientists, Eccles, Sherrington, Penfield, Benjamin Libet, who were dualists 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 then 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, the 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 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 do you think? 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 it's very beautiful.

Michael 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 in existence. It 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 mind. 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 about, of course, Schrodinger talked about the one or the original mind. There was 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 mind, 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 and mind comes from just inert matter. But I just think that's not going to happen.

Michael 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, 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 if you look... One time a reporter asked Bertrand Russell if he thought there was any such thing as human dignity.

Michael Egnor:

Right.

Stephen Post:

Now, Bertrand Russell was a devoted materialist, 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 Ben O'Neal or 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 mentally 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 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 this of course, this is the T4 project, the Tiergartenstrasse 4 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 Aryans. And so the German people reacted against this. And the same two principal investigators who handled the Tiergartenstrasse 4 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 their being differently abled nowadays.

Michael Egnor:

I have as my guest today, Dr. Stephen Post, and he has fascinating insights on the relationship between the mind and the brain, as well as the ethical implications for our understanding of that relationship.

Stephen Post:

Yeah, that relationship is so important, Mike, back in my Ohio days, 20 years at Case Med and I traveled all over with the neurologist, Joseph Michael Foley, who was just incomparable. We once drove down to Mount Vernon, Ohio near Kenyon College, and there is a geriatric psychiatric institute there. And one of the sections of that institute is devoted to people with the dual diagnosis of Down syndrome and

probable Alzheimer's disease, because as you know so well, being an esteemed neurologist that pretty much ubiquitously people with Down syndrome by the time they get into their late 40s or early 50s, see a decline in their mentation. And it's really kind of development in reverse. So they have probable Alzheimer's on top of the Down syndrome.

And Joe and I walked into this unit and we saw there were probably 50 people there being cared for so meticulously and so palpably kindly by a whole bunch of Hindu nurses aides, and apparently these Hindu nurses aides had gone down to Mount Vernon and they had their community there, and they were totally devoted to what they were doing. And they were not rude, they were not judgmental, they were totally accepting. Their tone of voice was warm and kind and uplifting. So Joe and I were so impressed, we took three or four of them out to a pizza restaurant in a nearby town, and we just asked them, we want to know what motivates you. How are you so committed to caring?

Because ethics is so much a matter of caring and respecting the dignity of these individuals. How do you maintain that? And they said, "Namaste," which all the listeners will know is the Hindu greeting, but it's not just, hi, how are you, it means I honor the divine in you. And so what they were saying was that they don't view these individuals as gone, as husks, as empty, as useless eaters, life unworthy of life to use a Nazi German term. But in fact, they see them as equally valuable because they're still sacred in their being. And this is where ethics has to get started with this population because otherwise every kind of abuse known to the species has been inflicted on individuals who were vulnerable and imperiled because they are deeply forgetful.

Michael Egnor:

It's interesting that that really echoes the ethics of Matthew 25 where Christ says that what you have done for the least of these, my brothers, you've done for.

Stephen Post:

That is a beautiful quote. And I quoted in Dignity for Deeply Forgetful People, and Joe Foley, who was a very fantastic Christian neurologist, he quoted it too. And in fact, we once wrote a chapter in an edited book about the relevance of that verse to the care of this population. So I appreciate your bringing it up.

Michael Egnor:

Sure. As I'm sure we both feel the same way about this, there's very disturbing trends in medical ethics regarding the care for people who have profound cognitive problems. You describe a concept that I actually had never heard of before, but absolutely chilling, and it's called preemptive assisted suicide. What is that?

Stephen Post:

Well, I had doubts, Mike, about including that chapter in the book, but the editors at Hopkins, they were fine with it. I use it to mean or to refer to individuals who want to avail themselves of assisted suicide while they still have the capacity to be the agents of their own deaths. And one typical case, a friend of mine from Cleveland, her sister was succumbing to more and more severe Alzheimer's, but she was still capacitated and she wanted to preempt the decline. That's the preemptive notion. So with her husband and her adult children, she organized her trip to go to Switzerland, and there is an institution there called Dignitas. There's language for you. And now her sister, who is my friend, was distraught over this because I have an email right here in my bulletin board, it says, "I can't get over it, how I wanted to go and be with her in her final years and let her know that I still loved her. And I'm terribly upset that she went to Dignitas."

And then I responded, "But you can't judge her. Don't judge her, and you can still love her, but this is what she chose to do." I don't recommend it. As you'll notice in the book, I give four or five very good reasons against this philosophical reasons, ethical reasons. And yet in the final analysis, I've known a few people who even though I recommended that they not do this part, see, partly my thing about suicide goes right back to Thomas Aquinas and his third argument, the first argument, well, it's hubris, God gives life. God takes life away. That's not too easy to sell in this world. And the other argument is that it's against the law of nature. Well, I'm not sure of that, but the third argument is that it has a kind of epidemic quality.

And so when you think about the young people 15 years ago who were jumping off that dormitory roof at NYU, they were following the leader who was really mimicking that was going on, and that's typically the case. There have been some episodes, by the way, among high school students in Waco, Texas that I've read about quite deeply. So instead of just one person, a young person killing himself, you had a chain of seven or eight, and Hemingway, Hemingway's father shot himself, Ernest Hemingway shot himself and his daughter killed herself. And you find this runs in family. So suicide becomes a way of dealing with the difficulties of life. And that's why I don't want to leave that as a legacy to my own kids who are growing up now. I just don't want to leave that for them because possibly in a pinch, they will emulate me.

And so I stay away from it. I don't recommend it. But on the other hand, I've known some very, very good people. When I was at the University of Chicago, I had two psychiatrists, both of whom were mentors. One was diagnosed with Alzheimer's, he had a loving family. He spent about eight years in a nursing home in Hyde Park. His family was visiting him often, they were stimulating him, reminding him of who he was with symbols and music. And he did pretty well. There was another psychiatrist who had no family, and he just didn't entrust himself to the system. He didn't want to die with a tube in every orifice, natural and unnatural. So he took 40 sequin walls and put a plastic bag over his head. And a few days later, it was in the Chicago Sun-Times on the front page. And that's a tragic thing.

And I suppose we call these individuals now, I don't know what the language means exactly, but live-alones in the literature, people who have no family, no support, no one to advocate for them, vis-a-vis the possibility of over-treatment. And for them, preemptive assisted suicide is somewhat appealing. I wrote an article in one of the major generalist medical journals about a guy who was a street clown in San Francisco, and he would do his performances on the library steps there down Market Street somewhere. And he was getting to the point where he was quite deeply forgetful. He had a diagnosis of probable Alzheimer's. And so before he declined too precipitously, he took his small bit of savings, $4,000 or $5,000, got himself an airplane ticket, and he went to Dignitas. And that's the last anyone ever heard of him. So I recognize that this is inevitable that it's going to happen, but my attitude, to quote another scriptural verse, "Judge not lest you be judged."

I'm not for this. I'm not an advocate by any way, any stretch of the imagination. And yet, I also understand that in our society, given the state it's in, that people are going to avail themselves of these opportunities. They don't have to go to Switzerland. They can go right up to Montreal. And I'm hearing that it's going on in New Jersey, but don't quote me, but it's not legal. It's not legal, and Oregon. So the assisted suicide laws in the US, you've got to be determined by two independent clinicians to be roughly, give or take, within six months or so of dying. You could have pancreatic cancer or you could have ALS. And if you still have the ability to do this to yourself, you're pushing the final red button that allows the poison to flow into your veins or whatever it might be, then you can do this.

But for most people with the progressive dementia of the Alzheimer's type, by the time they're within six months of dying, they have lost their capacity for decisions and actions, purposeful actions, a long, long time ago. So they're basically ruled out, and I think that this is what's going to happen is you're

going to see most of these places in the US in the next several years following alongside Montreal and Quebec, Switzerland and other such places, because it'll be viewed as discriminatory to disallow deeply forgetful individuals this "opportunity."

Michael Egnor:

Right. Right, kind of a sick twist. I see the assisted suicide question as really in some sense, three fundamental ethical questions, that is it ethical for an individual to commit suicide with medical assistance? Is it ethical for a society to sanction assisted suicide? And is it ethical for the medical profession to play a role in it? I think it's unethical on all counts, but I very much agree with you that we need to show sympathy for people who are in such an existential state that suicide seems to be the appropriate thing to do. There's a great deal of suffering going on there. It's a terrible state.

Stephen Post:

Although suffering, yes, while they are still insightful into their losses, and I use the word carefully, if there is a kind point in the progression of dementia, say of the Alzheimer's type, it is when people forget that they forget. And then they can have a relatively benign, not universally so, but a relatively benign emotional adjustment. They have lost the temporal glue between past, present, and future. They're living mostly in the pure present, which by the way, in the popular culture of Zenists, an ideal modality of being. I just have to throw that out. I mean, when you spend a lot of time with deeply forgetful people, you can't be too chronologically concerned.

But at any rate, yeah, these are individuals who are not suffering, obviously. I mean, you can ask that question, are they suffering? Well, I mean, if they're well cared for, they're not suffering and well cared for and not insightful into this kind of peeling away of capacities. And if people realize that underneath it all, they can be connected with, if we can just listen attentively, notice the subtle purposes in their activities, I think that there's oftentimes a lot more purposefulness in these individuals than we realize. But you have to have a special sensitivity to it and be open-minded about it, which is, again, why I don't like the word dementia, because it's just sort of them versus us. They have declined, they're gone. Whereas deep forgetfulness is, look, we all have our moments. I have my moments on the escalator of this building.

Michael Egnor:

One part of this that bothers me profoundly is the participation of the medical profession in the assistant suicide business. And in a way, a doctor carrying out assisted suicide is like a pilot deliberately crashing a plane. It's kind of the opposite of your job. I can't fathom a doctor going into work in the morning knowing that he or she will kill a patient that day deliberately. And it's the antithesis of medical practice. And if you think about it, there's no reason on earth why if a society wants to sanction assisted suicide under law that they have to use medical personnel.

Stephen Post:

Oh, absolutely true.

Michael Egnor:

They can allow judges to write prescriptions if they want.

Stephen Post:

Yeah, exactly. So Leon Kass, who was one of my... I was a teaching assistant to a course that he did in the Pritzker School of Medicine in Chicago. He wrote a book called Toward a More Natural Science, which is a classic. And in it, there's a chapter called Is There a Medical Ethics? And he's looking for somebody that derives exactly from the logic in Aristotelian terms of the purposes of the healing art. And so for him, the reason why the Hippocratic Oath so strongly forbids even counseling someone about suicide, let alone operationalizing it for them, is because the healing art should not ever be confused with the killing art.

Now, he does actually say that if this was ever legalized, you would not want to participate in it as a physician because of your identity and your formation. You wouldn't want to compromise your integrity, but you could have a paraprofessional group. Now, what would you call them? I have no idea. You could call them terminators, you could call them death busters. And so he doesn't use that language, but he suggests that it would be better than having doctors be so engaged.

Michael Egnor:

Right. I believe that the enlistment of the medical profession in this business is a deeply, deeply evil thing and it bodes horribly for our profession and reflects terribly on doctors and on the medical profession that we would tolerate this, let alone participate in.

Stephen Post:

And the logic you're talking about, I mean, it's a contradictory practice. It's as though, think about yourself, you're going into a doctor's office, let's just say your office, and there's a nurse who leans out through the door and calls into the waiting individuals in their chairs and says, "Mr. Davis, the doctor is ready to kill you now."

Michael Egnor:

Right. Right. Right.

Stephen Post:

Suddenly, everybody's freaking out. So the killing art can't be the healing art. You've got to keep those logics separate. And many of the people I've known who have been most seriously opposed to abortion. I know several of these individuals, they were initially taking on most of the responsibility in obstetric departments for elective abortions. And one of my friends who I knew in Cleveland at the Metro North Hospital, great guy, at a certain point, he just said, "I'm not doing this anymore because I was trained to bring life into the world. And that's what I take joy in doing, whether it's a C-section or a natural birth, that's where it all comes to, and the idea that I'm going to be spending the rest of my career doing D&C elective abortions or whatever, it's just not appealing to me." So he told that to his department chair.

And I was involved in these discussions, and the department chair wisely said, "Well, I think we need to respect your conscience. And so other people in the department can shoulder that responsibility. And we're not going to blame you. You have done your job, you've done it as well as you can, and now it's time to move on and we can fill the gap." But on the other hand, I've known some people who were really excoriated for taking this position here at Stony Brook. If you look at the OB-GYN department, it's a mix of individuals. Some of them are more comfortable than others, and they have policy. If you don't want to do abortions, you don't have to do abortions. And the medical students who are in the clerkship program, they are specifically instructed that they should not violate their moral conscience. And so if they feel uncomfortable participating or even witnessing abortions, then they don't have to be in the room.

Michael Egnor:

Do you think that that conscience exception is being threatened? My sense is that there is a rather powerful movement afoot to constrain our freedom to respect our consciences in this situation.

Stephen Post:

Well, this medical school we're in, the first founding Dean was a close friend of mine for 20 years, Edmund D. Pellegrino. He was also a friend of Joe Foley's, and Ed as a Roman Catholic, he was opposed to abortion and refused to do it himself. And then the question came to him, "Well, would you refer a patient to an obstetrician who would in fact perform their requested elective abortion?" And Ed wrote very controversially at the time, "No, I would not, because then I would be complicit," which is an ethical term, "I would be complicit in the act myself." And so that's where Ed came down. Now, a lot of people who are conscientiously opposed to abortion will actually make referrals. There are some studies on that.

It's an area where they're somewhat ambivalent, but they'll make the referrals. But I do think that physician conscience is crucial. How can you practice? How can you have an identity? How can you have integrity if you cannot have your conscience respected in areas that are very, very important to you? I think if we go that route, it's just really the end of medicine. Now, are we moving in that direction? In some areas. In some areas, I think maybe, it's gotten so bureaucratic and the expectations as employees to employers is really one of acquiescence sometimes, and it doesn't allow people the level of freedom of conscience and activity that was once commonplace.

Michael Egnor:

Well, my understanding is that referral for assisted suicide, at least to Canada, is required for medical licensure. And I could be wrong about that. I don't believe that clinic physicians are allowed to simply refuse and not refer.

Stephen Post:

Yeah, I don't think it should be required. A referral should not be required because many people have very strong opinions about this, and it violates their integrity. In the military, they have an expression for this, they call it moral injury. When you're taught, you go into the Army or the Navy, you're taught about non-combatant immunity. You're taught about proportionality, balancing harms with the circumstances and so forth and don't torture. But if you look at the people who were in Iraq, for example, who were involved in some of the torture and the killing, they all had post-traumatic stress disorder. And a lot of them are still in the VA medical centers getting help, because again, they were asked to violate their moral substance. And that's the thing that I think is so important. So I don't want to recommend that anybody goes into a profession where they can't be granted the freedom to express and operationalize their most deeply held convictions.

Michael Egnor:

Right. Right. But I do fear it's at risk. And I go back a lot, think about why on earth doctors are expected to play any role in killing any human being, that is euthanasia, assisted suicide, abortion, in all those situations, that is simply killing. And if society wants to sanction killing, it should at least do it not people who are in the medical profession who have an obligation to protect humans. And you can ask, well, why is that? Why is it assumed that doctors are the ones who should be doing the assisted suicide or the abortions?

And obviously to some degree, it's because doctors are acquainted with the techniques and the instruments and so on. But there's a deeper issue, I think, and that is that people who are advocating killing, want to have a medical predator. They want to wrap a white coat around the killing and make it seem as though it's an ethical thing, it's healing, it's preventing suffering, all sorts of things. So there's a deeply evil misleading why behind medical killing. So I'm advocating very strongly within the medical profession that we just wash our hands on this, that doctors agree never to deliberately kill a patient. It seems such a basic thing, but we're doing it a lot.

Stephen Post:

Yeah, they want the white coat. And if you think about this in terms of executions in capital punishment and the like, the AMA itself, the American Medical Association forbade physician involvement in electrocution or any form of capital punishment. And that's been in place for probably 35 or 40 years. There was a period of time when some doctors were so involved, but it was scandalous for them as moral beings. I mean, that's really what I get concerned about is the very being of a physician at the deepest level. How can you ask them to do things that are so much contrary to what they've been taught to do and not to do? That's the moral injury, and moral injury, I think it's one of the reasons, Mike, why we call it burnout. It's not just burnout. People get tired, they quit the profession. There's a lot of attrition, but it's also the moral injury. It's the moral injury of doing things that you're not comfortable with.

Michael Egnor:

Right. Right. So I guess the best thing we can do about this is to continue to speak out because I think there's a great deal of sympathy for our perspective within the medical profession. But a lot of doctors, a lot of people in the medical profession kind of think of it as something that they're expected to do. The resident training in the obstetrics may just think of abortion as some rather unpleasant thing that they're supposed to be doing as part of their training. And I really want to emphasize to people in the medical profession that you don't have to kill and that when you're killing, you're not acting in the medical capacity.

Stephen Post:

So I knew a kid from Queens and he was doing his clerkship in obstetrics, and he was Korean American, and his major identifying community was a Korean American Evangelical Presbyterian Church like you see on Northern Boulevard. And so that was who he was, but he wasn't sure about his views, wasn't quite sure about his views on the matter of abortion. And he certainly didn't fully grasp the right that we give him. And it's very explicitly allowed and encouraged not to be involved. And he, anyway, was involved in one of these D&C abortions where there's a tube, a plastic tube, and you can see blood and remnants of small body parts going into a pan. And after this was over, he had to leave the room and he went home and he was just unable to breathe for the evening. And he talked to me about this and he said he made a mistake.

He did something. He wasn't sure that he was conscientiously opposed to it, but he felt that he probably was. He just wasn't a 100% certain. Well, seeing all that and all of its graphic quality made him absolutely convinced that that's not something he wants to do. I don't think he went into OB-GYN professionally, but he understood that he was going to exercise his veto power and more power to him. Now, I have to say that I saw him even three or four weeks later in a small group in a reflection context, and he was still speaking about this and trying to process it, and it was quite a sign... He'll never forget

what he saw. Now, for other people, this is just routinized. It's just everyday activity. But for him, it was terribly contrary to who he wanted to be.

Michael Egnor:

I was at a meeting of the Accreditation Council for Graduate Medical Education, which is the national entity that accredits training programs for doctors. I was at a meeting about a month ago because I'm a program director in neurosurgery. I trained the young neurosurgeons here, and there was a session on the response to the Dobbs decision that overturned Roe v. Wade. On behalf of medical education, it is how do we educate residents, for example, to perform abortions in this new environment? And it was in Nashville that the meeting was held. I was sitting in the audience listening to this, realizing that here were and there's a panel of experts of national leading OB-GYN people, of attorneys and so on, discussing training residents to do things that in about half the states in the country are now felons, that this bizarre scenario in which the commission of such acts like abortion is sanctioned by many people in the medical profession when right now, in reality, these are felonies in United States. So I really don't think the doctors, nurses should be trained in these kinds of procedures.

Stephen Post:

That's amazing. Philosophically, Mike, I think ultimately the abortion issue, if you really look at it almost metaphysically, I mean, I'm not talking about social determinants of health and all of that kind of thing, which is important, but it really comes down to Aristotle's distinction between potentiality and actuality. So if you look at the sort of the dominant philosophical view, it makes no sense. It is argued that someone who is actually a moral agent, who is actually fully "a person," that they would have to accommodate an entity that is purely potential and unactualized. So as Aristotle pointed out in his view, I don't think he was right, actuality always trumps potentiality.

But if just on a meditational level, if we think about this, every one of us on the face of this earth began as the tiniest little speck of potentiality. And in the Christian tradition, we don't distinguish between potentiality and actuality. Potentiality is actuality, and that's why there are baptisms and baby showers and all kinds of things that go on. We try to create a culture of inclusion, but what we see in these occurrences is a culture of exclusion, sometimes very radical exclusion. And that's ultimately where I think most of the cards are on the table.

Michael Egnor:

Yeah. Yeah, it's a terrible, degrading thing. And Mother Teresa actually said one time when she visited the United States that one of the greatest evil that a mother kill her child, if you're not safe in the womb, then nobody's really safe.

Stephen Post:

It's just a geographical thing. But you can make comments about it, so to some degree, I mean, you're a neurosurgeon, so you know about all the things about brain death and diagnosing it. At what point is a person no longer a person by virtue of brain death? Well, there are arguments about this that go way back to Henry Beecher at Harvard, who along with Leon Kass developed the whole brain criteria. But people there, like Robert Veatch, a very famous medical ethicist, actually wanted to say, "Well, wait a minute. Even if your brain stem is working and controlling certain physiological mechanisms, if your higher brain is no longer operative, then for all intents and purposes, you're dead. That's called higher brain death."

The problem with that is, as you're well aware, even people who are in the persistent vegetative state, we think of them as dead. But Joe Fins, who's the leading ethicist at Cornell Weill New York Hospital, and a pretty good friend of mine, he came up with this idea about 15 years ago, called the minimally conscious state because he noticed that there were some rare patients who had been diagnosed as PVS, and the nurses were saying, "Wait a minute. There's something a little more there than meets the eye." And they were coming out of it. So instead of confusing the PVS thing, he came up with a new category. And that's now widely accepted.

But listen, I know Jewish neurologists, I knew two in Cleveland, and they refused to diagnose brain death because on their grounds, conscientiously even whole brain death, even the situation where the brain stem, the reptile brain, if you will, is no longer functioning, you still have warmth to the touch. You still have with respirator support, you still have breathing going on. And so it may not be integrated and controlled in a central way, but for them, the whole idea of stretching death beyond the point where someone is simply cold to the touch is unacceptable.

Michael Egnor:

Yeah, and I think that's a viewpoint that's very much worthy of respect. I've been trained and working in a system where brain death, biological death of the entire brain from the cervical mental adjunction upward is considered actual death, in which case organs can be harvested, et cetera. And I've declared many people brain-dead in my career, but I see that there are some very serious ethical issues there. And I don't consider it a settled ethical.

Stephen Post:

I teach in medical school and I don't write about abortion. And with few exceptions, I think the students view it really as a social political issue, a social determinants of health kind of thing, and that some people don't have access to elective abortion to the degree that others do. And if you look at the recent Supreme Court case where abortion is completely outlawed in say, Kentucky, but not in New York, then it just means the people from Kentucky need to get on a bus and come to New York. But that's very inconvenient for them and disruptive and expensive, and usually these are relatively poor people. So it gets boiled down to an issue of economic and social equity and equality and so-called justice, and that's what you hear the most about, but nobody really is solidly addressing the deeper metaphysical questions that are most important.

Michael Egnor:

And people skip over. If one talks about social determinants of health, if one is talking only about the sort of difficulty that one encounters, if you live in a state that doesn't permit abortion, want to have an abortion, but there are other social determinants of health that cut the other way, that is that, for example, Black children are aborted at a rate three times, at least three times that of white children. Poor children are aborted at much higher rates. And in many parts of the world, girls are aborted at a much higher rate than boys are. So there's lots of social determinants in the abortion scenery that are very important, particularly I think in the US the fact that the abortion rate amongst African Americans is much higher that are never brought up when we talk about social determinants of health.

Stephen Post:

Yeah, that's exactly right. And by the way, just linking this back to Alzheimer's, so some cases of Alzheimer's, as you know, are caused by an autosomal dominant gene. That's the Presenilin-1 gene on chromosome-15, I believe, and the more rare Presenilin-2, which is on chromosome-1. And these are

individuals who, if they have that genetic mutation, it will cause them to get Alzheimer's disease pretty carefully defined, usually by about the age of 40. But there are some cases on record of individuals in their 20s, late 20s, with Alzheimer's disease carrying especially the Presenilin-2 genotype. So this is not like the normal late onset Alzheimer's when people are in their 50s, 60s, 70s, 80s, 90s. It's about 2% of people at age 60, and it doubles every five years.

And so when you get up into the 80s, you're talking probably about 14 or 15% of the population given current life expectancies. Of course, it's much worse than Japan where people live well into their late 80s and early 90s on average. But so I was on a national public radio program with a woman from Chicago, this is probably 20 years ago, and she had decided to have a selective abortion because her fetus based on amniocentesis carried the Presenilin-1 gene. And she as a teenager had cared for her father who had the early... This is the rare early onset form of Alzheimer's. It only contributes about 2% of total cases, and it's very irrelevant to the general masses of people, but these are special circumstances. So she had cared for her father while she was a teenager, a young teenager, and had been very disruptive, of course, for her family. And she never herself got genetically tested.

You can't get genetically tested for any of the susceptibility genes like the Apolipoprotein E4, but you can get genetically tested at a testing center for the autosomal dominant stuff, which was what was affecting her family, obviously. And so she did not get tested herself. No, I'm sorry, what did she do? Yeah, she actually did get tested herself when she was pregnant, and she found that she carried the dominant gene, and that meant that her fetus carried it as well. So she wanted a selective abortion. And a lot of people reacted very negatively to her saying, "How much do you want to control the life and lifespan of your child? Your child anyway, could have 35 or 40 years of good life, could do wonderfully creative things, and maybe they'll come up with a real solution to the Alzheimer's problem during that period of time."

But still, she just didn't want to have anything to do with it. So I said, I don't condone this. I think how much should we be controlling the lives and the lifespans of our children? Well, maybe you can talk about certain conditions, Tay-Sachs and so forth, but this is really stretching it. But she wanted to have it anyway, so I said, "Well, look, I'm not going to condemn you," judge not lest you be judged. And I think she went ahead eventually and had her selective abortion. But that raises the question of just how much are we moving toward perfectibility as a notion of human fulfillment? Because I mean, if you think about it, any selective abortion is going to be based on the age of onset of the illness. And it could be immediate, it could be 10 years down the road, it could be 80 years down the road.

And also the severity, is it something that's very severe or not so severe? And so I don't have decisions in my pocket for individuals, but I think they have to consider these things much more carefully maybe than we are, because these days, selective abortion for a... When I was at the University of Chicago, we had a case where a mother who had not been able to get pregnant for many, many years, she finally got pregnant. And then they showed on ultrasound that the fetus, I think in its seventh or eighth month, had a clear cleft palate. And this mother had a particular thing about cleft palates. And even though they're surgically correctable now in remarkably effective fashion, she still wanted her selective abortion. So she got her selective abortion and she never got pregnant again.

Michael Egnor:

Well, the tragic irony there is that one could consider the willingness to kill an innocent human being because of a medical problem like that, as kind of a negative aspect of a human being's personality, but the same human beings were killing other human beings because of the cleft palate. I think it's horrendously evil. It's a sad state that our society is in and sad state that the medical profession

participates in. Well, thank you so much, Steve. It has been a privilege and a pleasure to talk with you. And maybe we can do a lot more of this because these are fascinating topics.

Stephen Post:

Sure. If anybody wants to get a hold of me, my website is Stephen with a PH, gpost, stephengpost.com.

Michael Egnor:

And your new book, Stephen, what's the title?

Stephen Post:

It's Dignity for Deeply Forgetful People: How Caregivers Can Meet the Challenges of Alzheimer's Disease, and it's out with Johns Hopkins University Press, and it's having a pretty good impact.

Michael Egnor:

Well, I'm getting that book and I look forward to reading it very, very much. And I just want to thank you for joining us.

Announcer:

This has been Mind Matters News, explore more at mindmatters.ai. That's Mindmatters.ai. Mind Matters News is directed and edited by Austin Egbert. The opinions expressed on this program are solely those of the speakers.