

Pulled Up Short with Stanton Wortham

Could dementia be a gateway to mystical experience?

Featuring Mark Freeman with Stanton Wortham (host) and Suzanne Kirschner (commentator)

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Stanton Wortham 0:00

Welcome back to another episode of Pulled Up Short. Thank you all for joining us. We're excited today to have Mark Freeman from the College of the Holy Cross, and Suzanne Kirschner, also from the College of the Holy Cross. We appreciate you all being with us today, and we're excited to hear from Mark about a rethinking of dementia that he's done in a new book called *Do I look at you with love? Rethinking the story of dementia*. So Mark, please tell us how we could think of dementia as something that's not just a loss.

Mark Freeman 0:30

Okay, will do. Let me provide some background context before I launch into the substance of this episode. For over a decade, I sought to tell the story of my mother, who had been stricken with dementia back in 2004, paralleling each chapter of her life during that period with my own written chapters. Many of the episodes recounted were tragic: a vibrant, intelligent woman was being taken down by a dreaded disease, and at times, it seemed like the only story to be told was one of painful demise. Other times, though, were really quite beautiful and called for a much lighter touch, something more dementia-friendly, you could say. Once my mother left us back in 2016 at age 93, it was time for me to draw together the various chapters of her life into a larger story. The challenge was how to tell it. Ultimately, the story emerged as a kind of tragicomedy, by which I mean a story that includes the full range of lived experience from the awful to the awesome. So that's really what I'm going to be talking about today, and the way I want to do it is by describing a quite remarkable transformation that took place over a period of time, fairly early on during her dementia. I need to provide a little context for that too.

I'm going to begin at the beginning when my mother landed at Tatnuck Park, an assisted living place in Worcester, Massachusetts. This was a period that was pretty hellish. Having no memory of our having visited a number of different places before choosing that one, she was convinced that she had been put there against her will. Having no memory of our having visited her frequently, she would sometimes speak of being alone and abandoned. She would sometimes get very angry too, and there really wasn't a blessed thing that we could do to stop it. She would say things like, "I think I would *know* if you were here." So this was difficult: it was difficult for her, and in all honesty, it was difficult for me and my wife

– it was hard to give all that care to someone and have the response be resentment over what you're supposedly not doing.

But the main thing that was hard was seeing my mother coming undone and seeing her suffer on account of it. One of the other things that was really hard for her at the time was the fact that she'd suddenly found herself among all these *old* people with walkers and wheelchairs and all the rest. She would often wonder, "What was *she* doing there anyway?" People there saw her as different too. For instance, when there was a fashion show, she was the model. When they had their annual holiday party, she'd be working the crowd like a pro. She'd dance sometimes too, and people would marvel at her moves and her grace and so on. One year in fact – I can't recall the exact event – she was chosen as the 'Belle of the Ball' or the 'Prom Queen,' and alongside the king, they danced the night away. So there were some good times.

But then she would sink back, either in protest or rage or utter confusion. The protests were vehement. "I know I can still drive just fine," she would say, "I've always taken care of my own papers. I've never been late with a check." When I would question these abilities, as was sometimes necessary (or at least seemed to be), her response could be swift and sharp: "I'm not an imbecile," or "You're treating me like a child." "What do you want, Ma?" I asked her one day. Her answer: "I want to be a person." So at this stage, there was a large disjunction between what my mother was and what she was in the process of becoming, namely, a once able-but-no-longer person. And she knew it. So it was as if everything was crashing down – all the things that had defined her, in her own eyes, were coming undone. *She* was coming undone, and she felt it acutely. What made the process even more confusing and painful was that she really didn't know why. "If only she could have let it go," I wrote in the book, "if only she could have given herself over to her situation and just lived her life, unhampered by all the cultural scripts and narratives that permeated her life." Here's a passage from the book that speaks to this, and I wanted to read it to you, with a few minor edits:

It was one of those fall days in New England that demanded your attention. Mom and I decided to take a drive up a country road toward Mount Wachusett, which offers vistas of the lush valley below, the mountains of New Hampshire to the north, and on a crystal clear day like that one, the Boston skyline. I tuned the stereo to a local classical station, and up we went, climbing the road to the mountain, music playing, the sky blue, the leaves beginning to turn, shaking loose, skittering across the road. And she was transfixed. "Beautiful," she said. "It must be peak now. Such a pretty road. Beautiful, beautiful day. What a day! Spectacular day for a ride like this. What a spectacular, beautiful day." And so on. It wasn't actually peak yet, but no matter. For her, it was close enough. Each statement she made, even if exactly the same as the one uttered the minute before, was brand new. So for a moment or two – and I assure you only for a moment or two – I envied her. That day, I really couldn't be there with the world like she was. I kept moving in and out between the welter of colors and this-or-that-issue that had to be thought about, between the incredible vistas and my mother's fate. But that day, for a few hours, she was happy, or something like it. I can't pretend to know exactly where she was, but

wherever it was, it did seem to bring her a kind of oneness – a full immersion in the world, untouched by all the chattering stuff inside our heads that keeps us from being present to things. Whether wittingly or not, my mother had given herself over to the world at these moments, such that it could appear and reappear in all of its bounty and freshness and goodness. She was truly awestruck, and rather than taking pause and reflecting on the spectacle before her, she became awestruck once more – taken aback by what the world could be, by what the world is, if we could attend to it enough to truly encounter it.

One more brief passage:

Some of the repetition I witnessed that day was merely a function of the fact that she couldn't remember what she had said moments before. But it wasn't only that. There was a kind of redoubling at work too – an intensification and underscoring of what she was seeing and feeling and being. And this suggests that things can be revealed even in the dreaded and dreadful depths of dementia.

Stanton Wortham 8:50

This is a fascinating idea, because, of course, as you say, most of us think about dementia as just a matter of loss and fear. So you're not denying that. It's clear that that's part of what happens as well. But you've suggested this notion that people suffering from dementia sometimes have access to an experience or a way of orienting to the world that has positive dimensions. I'd love it if you could elaborate a bit more on that. How is it that dementia opens up the kind of un-self-conscious experience you're talking about? What exactly does that look like?

Mark Freeman 9:28

Let me offer one or two qualifications. The first is that the sort of thing that I just described certainly does not happen with all people who have dementia. I don't even know that it happens with most people who have dementia. The only "case" I really know is my mother's. So, probably the biggest qualification I would want to offer here is that the last thing I would want to do is say to all the people out there, caretakers and the like, is "this is what dementia can be," because for a lot of people, it's just not that at all. As for the idea of positive consequences or something somehow being gained, I can go with that idea. Although, when I think about positive consequences, that is, things that happen in the aftermath or gains that are made, those ideas connote something more long-lasting in my view, and these experiences were pretty transient. So if we want to talk about positive consequences, we should certainly recognize that they were quite momentary.

The central idea: the notion that somehow the kind of "self loss" that's brought about by dementia can actually bring about something akin to mystical experience – I'm still on board with that idea. And what I would want to say is that for some people (and of course, this is both ironic and tragic), the loss of a kind of conscious, reflective, critical self can lead to un-self-conscious modes of relating to the world that are, in fact, akin to/reminiscent of/related to certain forms of mystical experience. I

emphatically do not want to equate them. The relationship at hand is less one of identity than significant similarity. I know I'm sounding extra cautious and qualified about all this, but I really had to be in formulating these ideas. I neither wanted to romanticize dementia, nor did I want to pathologize mysticism. I was also well aware of the fact that, unlike those experiences that may emerge through prolonged, disciplined ascetic practice, for instance, my mother's experiences were unbidden, unsought, and had as much to do with the loss of memory, in a way, as anything else. Of course, I can't know this for sure because I can't know what went on in her mind. But I would venture that her experiences also didn't have quite the same phenomenological quality as what's been considered in the context of mystical experience – of the sort, for instance, that William James has discussed and others. Qualifications aside, I became convinced, and I remain convinced, that the relationship at hand is more than incidental, and that as I put it in the book, "Things can be revealed even in the dreaded and dreadful depths of dementia, again, that are vitally significant and supremely real." One more very brief passage – it's the last passage I'll be citing – speaks to this. I wrote at one point,

The very extremity of my mother's condition has ushered in something new – something that not only testifies to what remains, but also to what grows, what bursts forth in ways that surpass some of the limits of ordinary life. There's real promise in such experience, tragic though it is. And it's important that it be recognized and, painful though it may be, welcomed.

Stanton Wortham 14:04

So these commonalities between dementia and mystical experience are particularly interesting. I hear you when you say that they're not exactly the same, and you're not trying to say that dementia is a route to what mystics and others have been seeking through those kinds of experiences. But I get that there are interesting commonalities between the two. One of them seems to relate this notion of a loss of self with moving beyond the self. I'm curious if you could say a little bit more about that. It seems to me that we tend to think of 'self' as something that's bound up with what we remember, who we are, and various properties of ourselves. I'm having a hard time thinking about someone who is suffering from dementia, who has lost pieces of memory and other things. How can we imagine what it is to have a self and lose it, if the self is disintegrating or not there in the way we traditionally think of it?

Mark Freeman 15:10

That's a complicated question. I guess what I would say is this – let me go back to that notion of dementia's tragic promise just for a moment. You know, in some ways, my mother went through a phase where she was, one might say, a victim of selfhood. I don't want to get into what the exact definition of self is, but I guess I'm relying very broadly on the kind of conception that James and others have offered: a kind of "I-me" dialogue, a kind of self awareness or self-consciousness. And when I say that she was a victim of selfhood, she was a victim of her own critical consciousness. In other words, she had an image in mind of an autonomous, self-sufficient, competent being, and there was a part of her that through that reflective consciousness knew that that was in the process of diminishing. It was when she was able to attend to something other than herself, and to do so in a fully unhampered and present way. And again, it could be taking her to a concert. It could be a really good glass of wine;

she always liked a really good glass of wine. It could be being in the presence of a great-grandchild. That's what I would say about that.

Now, I remain uncomfortable, on some level, continuing to use the language of loss. Seen from one angle, what she was undergoing could plausibly be construed as loss. But seen from another angle, she was moving to a different mode of selfhood, or maybe personhood is the better word in this context – which is to say, a mode that involved less self-critical scrutiny, less self-consciousness, less internal dialogue. I can tell you that in later phases of her life, there was virtually no internal dialogue, and there was virtually no memory to speak of. Some people might have looked at her experience, such as it was, utterly in the moment, and they might say, "She had lost herself. Her self no longer existed." And maybe on one level, that's true if you use that kind of "I-me" conception. But on another level – her mode of being in the world, her mode of comportment, her wit, her love of music and food – all that remained for a while. All that remained. So this was interesting: as a narrative psychology person, I had assumed with most other people that selfhood and autobiographical memory are pretty much coextensive, right? So from that perspective, if in fact you were to lose your autobiographical memory, it would follow, at least theoretically, that you would lose selfhood. As I said before, there's no question that she lost some stuff. But in a way, I would be prepared to say that there were aspects of her selfhood that very much remained. And so some of this has gotten me to rethink aspects of the very narrative psychology I kind of thought I knew. In that sense, her experience proved to be a real education for me.

Stanton Wortham 19:16

So there was a kind of immediacy, a lack of reflection and mediation. She was able to experience things without these other dimensions that are brought by the reflection, and you're saying that there was something about that that was positive. There was something to be admired or valued in that. It's also interesting to me to hear that you're saying certain parts of her self – her tastes, her pleasures – that those things really weren't impeded by this loss of that reflective layer.

Mark Freeman 19:54

I would say they would change to some extent, but they remained visible and alive, well beyond the loss of her autobiographical memory. So, you know, that in itself has gotten me thinking about selfhood and what it's all about in a somewhat different way than I had been, a more comprehensive way, I think. And of course the reason I wound up drawing some kind of rough parallel between what she was going through and certain elements of Buddhism or mindfulness practice is precisely because much of the same language is used. I mean, if we go to James's chapter, for instance, on mysticism from *The Varieties of Religious Experience*, he frequently talks about, not necessarily the loss of self, but maybe the abeyance of self and the abeyance of the kind of critical rational consciousness that usually characterizes much of ordinary life. If we look at the four characteristics of mysticism that he enumerates in *The Varieties of Religious Experience*, there's a good deal of overlap between what he's saying and some aspects of my mother's experience – I emphasize overlap, some similarity, not identity.

Stanton Wortham 21:33

The way that you just formulated it is helpful for me: it's not that she lost herself, it's that it went in abeyance. That shift from loss to abeyance helps me to understand what you're getting at. So to wrap up, could you just say a little bit about how this changes our conception of aging and dying? If we don't think of it as primarily decline, forgetting, and deterioration, how should we think about it anew, given the insights you've been able to develop from being with your mother through her process?

Mark Freeman 22:09

Yeah, that's another really good and important question. Here, I suppose I could just say a little bit about my own changing conception of how aging and approaching death might be seen. So here, I wouldn't want to just focus on mystical type experiences. I really only address those in one chapter of the book. But I would want to say something about coming to see the process of aging, and even dying, in a different light. Of course, it's hard to deny the reality of decline, forgetting, and deterioration. So the last thing I want to do is bury that narrative. That would just be unrealistic, and entirely too wishful, I suppose. But there is another narrative that can be told alongside it, and that one has to do with the preciousness of life's transience, and being able, in a sense, to witness it: the beauty of nature, and so on. Sometimes when people knew what I, my wife, and our kids were doing, they would say things like, "Oh, what a burden it must be," or "You're great for doing this," or something of that sort. In other words, the fact that you could endure this unequivocally tragic dimension and be a caretaker is so laudable. And we never felt that way about it. What we really came to feel is that this is just one way a life can evolve. You know, this is life, and this is the direction it went in. Let's make of it what we can. I mean, we could have bemoaned all of the stuff that was going on, and there were some people – relatives, for instance, some friends – who did exactly that. They were so caught up in what she had been and what she no longer was that it was difficult for them to experience her as anything but broken. And in one case, somebody even said, "We lost her a long time ago." But we didn't lose her. She changed, and to have the opportunity to have been with her through that change and to have shared some of it was something of a gift. Again, I wouldn't want to sugarcoat it. There were phases that were bad news, but that wasn't the whole story.

Stanton Wortham 25:12

Great. I like that way of formulating it. So thanks to Mark for bringing us this insight about dementia and some of the dimensions of it that we don't normally reflect on. Now, I'd like to ask Suzanne if she would come in and ask a couple of questions and engage with Mark about this fascinating topic.

Suzanne Kirschner 25:28

Certainly. Hi, Mark. Thank you. I want to say first that I'm sure that the ideas that you've just talked about in this podcast, and that are drawn from your book, are going to be valuable to many people who have or have had a loved one with dementia. Not only because so many of the situations that you recount are very familiar/will be familiar, but also because I think you really are trying to offer some alternatives to many typical narratives and tropes associated with the dementing process. But what I want to ask you, then, is: are you saying that you think that your mother's distress and her panic at

those times – at those moments – were entirely a function of this culturally constituted sense of personhood that was sort of instantiated in her? Are you saying that because that [cultural ideal] constituted her sense of personhood, that that is what her panic and distress were caused by? Or are there aspects of her distress that you wouldn't want to attribute only to that? And if so, what are your thoughts on where those other sources of distress might be rooted?

Mark Freeman 26:53

Hmm, great question. No, I certainly would not want to say that her distress or her rage were entirely a function of a prevailing cultural narrative about independence, self sufficiency, and so on. No, I would probably want to invoke some kind of existential awareness that can plausibly be said, on some level, to predate those narratives. That is, insofar as one is used to functioning in a particular way, and is suddenly shocked and dismayed by being unable to function in this way and having some awareness of it – I would guess that basic kind of phenomenon existed well before the upsurge of individualism and all the rest. I would likely hold to the idea that, indissociable though those dimensions may be (which is to say, the internal and the cultural) at the level of experience, I'd probably still want to dissociate them analytically and say that there was something that no doubt would have registered in virtually any epoch. One way of addressing the question is to say that there are certain aspects of contemporary culture – not that she would necessarily be able to articulate those, mind you – that are just part of the fabric of culture and that probably intensified and exacerbated the problem at hand. There were times when I tried to "deconstruct the cultural narrative," precisely by saying some of the things that you mentioned, where I could say to her, "You know, Mom, it's okay to need people. It's okay to be vulnerable." So there's a sense in which I tried to convince her that the narrative of the sovereign self wasn't the only game in town and that maybe by acknowledging some of the fragility and vulnerability and so on, she could just be more comfortable in the world. But it really didn't work. It really didn't work. By the way, she did the "I'd never want to be a burden" thing for years. Yet when she was in assisted living, she came back at time and said, "So what? Nobody wants me?" Classic stuff. So the burden thing is something that may not be the leading line once reality takes hold.

Suzanne Kirschner 30:12

The passage that you read, which was from a chapter in your book called "Presence" – I was glad that you chose that, because when I read the book a while back, I actually wrote in the margins of some of those pages: "Oh, this is beautiful writing." Of course, in that chapter, you make your longest case for this idea that... she's truly encountering the world. You call this an "ecstatic presence." One thing that I associate with Buddhism [which you associate with this state] is non-attachment. And of course, attachment can mean attachments in this context to anything, right? To our desires, to the objects of our desires, to suffering, to anxiety, to all our thoughts and feelings, including our loves. So, attachment also to the people we love, as well to people we're ambivalent about. It's all attachment. So those attachments are felt and manifest in how we relate to each other. But my question, then, at the end of all this is this: how does this ego loss – this un-self-ing that you describe as being, at least in these moments, a good and even enlightening development for your mother – how do you square that with

the fact that it also in some ways entailed not connecting or being connected to people in the same way – including to you, her son?

Mark Freeman 31:55

There's a lot to say in response to the question, but I'm going to just focus mainly on what you asked towards the end. I would say that, at least this is my understanding, when the idea of detachment is used in Buddhism, it's often detachment from the kind of grasping and appropriative desire that leads us to craving of one sort or another, and leads us to appropriating the world rather than being with it. But I don't think that that kind of detachment, if we even want to use that word, necessarily entails in any fashion the diminution of the kind of relationality that we're able to have with others. It simply is a kind of fact that in my mother's case, even when she really had lost a lot of her memory, in terms of concrete episodes and epochs and so on – I mean, she was married to my dad for 30+ years and barely remembered him. When I asked her about the partner she was with after my dad died, I said, "Do you remember Rocky?" She said, "Sounds familiar." So there's no way she could tell a story about her past, really, eventually. She didn't have a past "to speak of," but she still had a lived experience of relatedness with certain people – and truthfully, me above all, mainly because I was there with her – that remained. It was difficult to know how much of that was memory, and how much of it was a kind of pre-reflective relationality that somehow got preserved, even amidst the deterioration of memory. Because those modes of relating did remain until pretty late in the process. Now it's possible that I've convinced myself that some of that remained longer than it really did. As you know from the book, in the later phases of her dementia, I often had to reintroduce myself, say what my name was, where I was from, was I married, did we have any kids, and all the rest. Sometimes she would pick up that thread and say, "I love you." So what was that? Was that a deduction that she somehow made on the basis of the conversation? Was it a kind of memory that emerged as a function of what we were doing? I don't know. I don't know.

Stanton Wortham 35:22

This was great. I really appreciate you're doing it. Thanks for listening to this episode of Pulled Up Short with Mark Freeman and Suzanne Kirschner. Please join us next week when we have an episode with Andy Hargreaves arguing about the centrality of social class. Please also check out our partner, the American Anthropological Association at their website, americananthro.org. Subscribe to Pulled Up Short if you haven't already, and follow us on Twitter @PulledUpShort.