How I Helped Reverse My Father’s Rapid Cognitive Decline—From Across the World Transcript

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Introduction and James Maskellu2019s background

Hello and welcome to this session of the Reversing Alzheimer's Summit. I am your summit co-host, Doctor Kristine Burke, and I am joined today by not only my fellow summit co-host, but also my business partner and co-founder in China, our brain health software company.

Mr. James Maskell. James has been involved in the functional medicine community for over 20 years. He has made groundbreaking progress through his efforts with the evolution of medicine and the functional Forum.

He has written two bestselling books, The Evolution of Medicine and The Community Cure, both focused around making this type of work and care available to more people.

So I am beyond excited to welcome James to the summit today and to share him with all of you. Welcome. Yeah, great to be here with you, Kristine. Thanks for having me.

Absolutely, absolutely. So, you know, one of the things that we've talked a lot about is how we each kind of got into this type of work. And I would love for you to share how your passion for reversing cognitive decline came about.

Yeah. So, first and foremost, this is a family thing for me, too. I remember being a young child and got to see my grandmother, who I really didn't know that well at all growing up.

And then witnessing things like, she couldn't tell the difference in me and my cousin Nicholas. She couldn't tell the difference between my dad and his brother.

They are twins, but they didn't look that much alike by the time they were 50. At that stage, just, you know, just, witnessing what this looks like and the amount of care that was needed and, and how tricky the whole situation was.

And, and actually, what a wonderful, in retrospect, wonderful situation she had at home with full time carers and, you know, all of the like comfort of being in the place that you're familiar with.

So then, I didn't really think about it that much. Again. For a long time.

Personal story of cognitive decline and mold exposure

I was triggered a little bit when I went to the 2017 conference where I first met Dale Bateson and was just inspired by him and his manner and what he was working on and read his book.

I think, you know, we both, inspired by him. But then again, you know, you and I had various conversations of, of different ways to implement this, and you were sort of going on your path on this, clinically to become an expert.

And then it really hit home, in December 2023, where I got a call from family member or friend in Cape Town, South Africa, where my dad live, saying that my dad had had a rapid cognitive decline.

They didn't call it that at the time. They were just like, he's in bed. He's not opening his eyes. We're not sure what's going on. He couldn't remember his pin number. Now he's there.

So I just took the flight home as soon as I could. Two days notice. Called you, and, you know, you said something at that moment, which is essentially that if it if the cognitive decline is that rapid, then it's always an infection.

So look for an infection. If there's no infection, then look at his apartment and see if it's moldy because it can be the same kind of feeling. And I showed up armed with that information, and I took what you said very seriously and also made sense to me.

And I first saw my dad and he was completely comatose, like, indistinguishable from death, very like breathing, eyes closed, non-responsive, all of that.

And then as soon as I realized that we weren't going to have an interaction, then I took the car and went to his house and saw an extremely moldy apartment.

It had been a very wet winter and a wet spring, and this was now December. So was just the end of spring and yeah, you could see it on the wall. You could smell it as soon as I walked in.

I know that smell. I know that what it feels like and, you know, my mind started to wander straight away to conversations that he and I had had over the three months since I'd seen him in the in the US summer early that year, of him being tired and wanting to stay in bed and being cold, and it all just started to make sense.

So I knew then what was going on. No one else knew what was going on, and the medical team and all the friends were all saying, look, this is death. You know, prepare for it.

So I started to do that. But I also, you know, had in the back of my mind what you had said. So a few days later, we are taking him by ambulance to a friend's house to have the final days together with close friends by the sea, in a beautiful place that I grew up in one way or another and piece by piece, things start to turn back on.

You know he has a bowel movement. He, can keep his eyes open. You know, I can literally pick him up and put him in a wheelchair wheel and outside, and he can look outside.

And within two weeks, the medical care team there that has specialized in this area, geriatricians and palliative care doctors are like, well, he actually doesn't have a terminal illness.

And, you know, it was quite a amazing moment to realize that one. You were right, right from across the world without ever having seen him or of having talked to him.

And that to recovery was starting from a very, very low starting point. Yeah. And just so it's just so impactful to hear that story recounted. And, and to realize that it's, you know, through no fault of their own, that care team there just hadn't been exposed to these ideas or hadn't experienced the change that can happen with that.

And, you know, I just think there's a lot there's a lot to learn from that experience. What do you feel like were the big moments that you took from that?

Well, the one major thing that there were many things and there still are things. I mean, I'm learning all the time from this experience. You know, you have a lot of judgments about what people should do for their family members now that I know this.

But I also now understand what it's like to live on the other side of the world and to, you know, understand what it takes. You know that many, many things on that end.

But I guess the key thing was, and I would just love for everyone to understand this, is that if you're the kind of person that comes on the dementia Summit or the also Reversing Alzheimer's Summit, you may be better informed than the whole medical system.

You know, and you may know more than I did at that moment. I was right, and I knew more. And ultimately, it's very intimidating to be with doctors who this is their job all the time, and they have no idea what you're talking about.

And you don't have to be a sleuth to kind of put the pieces together and see what's happening, especially if you've

been educated by someone like yourself.

And so the first thing is that you have to have confidence in your own ideas. And I think that I had enough confidence in my own ideas to say, look, this is what's happening.

And although early on I didn't get a lot of support because they were like, well, whatever, when it started to reverse in the other direction, then people started to pay attention.

So I think I can't underestimate that enough or underscore that enough because, you know, ultimately, and I don't know if you found this, I'm sure, that that is a big stumbling block, is that this is new.

No one understands multimodal, chronic illness. The people who understand it the best are the emerging network of precision and functional medicine doctors.

And therefore don't expect people to. Don't expect doctors who'd be doing the same thing for a long time to suddenly get it. Yeah, we've definitely run into that very frequently with immediate family members or extended family members of the patients that we're working with who have never heard of this.

And, you know, how could it possibly be that none of the other doctors know anything about this or believe in this? And it's it's hard to help them to to build that confidence that this different thing really is and can be amazingly effective.

Lessons on trusting your instincts and community support

And sometimes I remind people, you know, there was a time when telling doctors they should wash their hands between doing an autopsy and delivering a baby, because there were these invisible things called bacteria that could cause an infection when that was heresy and nobody agreed with that.

So these disruptive ideas in medicine, they often come at the expense of not being widely accepted until the evidence is incontrovertible. And I feel like we're we're starting to get to that point.

But it really is true that you have to be confident that there is data that supports this, and you should feel confident in advocating for your loved one in that situation.

I think one of the other things that was really impactful in your experience was the community that you had, the community you had around supporting your dad where he was and the community of people that you had here supporting you.

And that, of course, is also your book, The Community Cure, because it's such an important part that support for healing. How did that how did that play out for for you guys in the different stages of this?

Yeah, that's been a huge learning as well. Actually. One thing I want to say, which I have never said before, which I think is impactful, is, you know, at that time when I was first with my dad, he was aware that he was dying, you know, and I think he was in the position that he thought that this was it.

And I can remember some of those conversations, him sort of having well, like, this is it for me and it's fine. And I, you know, and and being okay with it.

But I was also thinking to myself, what was that? What would be happening now if I was living in a, in a country where it was legal to euthanize yourself?

Like if I lived in Canada right now, would we be euthanizing him? And I still think about that. But Cape Town doesn't have those rules. And also I because I knew what I knew, I was sort of in in that process too.

Yeah. The community is so huge in this conversation because one is that my father has built a huge community of

reciprocity in Cape Town, having lived there most of his life and having been involved in an intentional community where many people, you know came to care for him, it's been journey for them, too, because many of those people are in their 70s and he's in his 80s.

So like, they're seeing firsthand a little bit of like, you know, what might be in store for them, terms of like, what happens once you can't drive your car or, you know, those kind of things.

So there's actually been been, I think, healthy for all of them. And and they have said as much. And I went back this year and had extremely interesting and powerful conversations with people who who this has affected fairly significantly.

I would say, yeah, on the community side, first of all, the early, the early times, at the time when I was there for that month, it was it was community palliative care, right?

It was people coming over connecting. We were staying in a friend's house. I was there, everyone was pitching in. We had some support for some of the sort of, gnarly parts of taking care of the elderly.

Right? We had some support there, but we were able to really be present and connect there, and that was really lovely. And I and I really enjoyed that time and being present with all of those.

But I think it speaks to a bigger piece, which is that it seems to me, through all the work that I've done and writing a book about group visits is that, you know, one's community and one's connections is such a critical part of whether or not you move towards chronic illness or move away from that, that ultimately, one of the earliest questions that we could be asking of anyone that is any in this direction is what sort of support network do you have for yourself in your community so that you know you are as best supported?

And it's one thing to be best supported in your journey away from dementia. But what is the support to just do new things, to make new diet choices, to to make new exercise choices, to make new friends, to connect.

And that's just one of the things that I think is critical. And my recommendation to anyone who's listening to the summer is start to think about those kind of things now, because the degree to which you'll be, you know, to which you will progress and the degree to which you can make it back are all dependent on the quality and quantity of your social relationships.

Yeah. I would absolutely agree with you. We really find that to be true in the work that we do, that there's such a need for there to be a support person, and it doesn't necessarily have to be a caregiver like a full time caregiver, but you need someone to support you.

You need an accountability partner. If nothing else, you need someone to help you organize and implement all of the changes that you need to make to regain your brain health.

Once it's starting to decline. That's no small task. It really does take a community of people. It takes a community of staff to do it, and health coaches and the dietician and the clinical team.

Just a lot of support around the change that has to happen to help that person. Yeah, and I think there's there's like professional support teams. So in your office you have this whole team approach.

And that allows different people on the team to work together to use to work with the patient and get that support. There's the there's the sort of familial support to the spouse, significant other children and those kind of things.

But then there is broader support, too. I mean, I'm I'm very inspired by the models that I've seen where there's like elder people and children, you know, together.

Because I guess one of the things that as an economist I've seen in my efforts to really think about transformation of health care is the sort of the way in which one person helps another person is really like where the leverage is.

I think, for for transforming health care. And if you're listening to this and you're thinking like, well, how do I think about that? You know, we you mentioned accountability partner earlier.

We have done some some work in this area and found that, you know, accountability while needed, is not really kind of an aspirational idea. We would put people in groups and we would call it a progress partner.

And that progress partner, even though it was the same thing, just sort of resonated with people and they wanted it. It was sort of aspirational to have a progress partner wanted assumes progress.

Right. And to you're all agreed on the progress. And I would just say that if you are thinking about your family member, maybe you're thinking about your new parent, or maybe you're thinking about yourself, you know, starting it takes a while to build relationships that can be of mutual value.

And to start now, because ultimately you will want these kind of relationships, you know, all the way through your life, and it takes active work to do them.

I found that building using online tools to create offline connections can be valuable. It's easy to find people locally now who might be interested in the same thing as you, and I think that's a critical way to think about building your social support network, to avoid chronic disease today and and in the future.

In fact, at the beginning of my book, I think I gave a stat that you are 36% more likely to get Alzheimer's if you have no social network compared to a really solid one.

So there's already science. And by the way, it's not just Alzheimer's is every chronic illness. Yeah. Wow. That's just something that isn't often thought about in medicine in terms of being such a critical piece of the of the healing puzzle.

And it really needs to be. Well, it makes me wonder what, you know, what we need to have available for people. Like what? What would have helped you out outside of our conversation?

Right? Like what would have helped you if it had been available or at your disposal to help you help your dad? Well, first, I think, you know, obviously every clinic that's dealing with dementia should have the true neuro software.

And I'm biased now because it's out in the world and we've made it together.

Building support networks and changing care models

But, you know, if if every memory care center dementia related group was using the software, first of all, you would know what was happening with my dad because the score for bio toxins would be zero.

So everyone would know this is a bio toxin illness. Let's take the steps according to that. And I wouldn't have had to like, convince everyone you know.

Second, even where he is today, there are people that are in the service of his health, you know, so he's in a care facility which has full time care because he needs full time care.

And there are like loving, connected people that are working there. I mean, I think you have to really care about working with the elderly to make that your full time vocation, you know, because in South Africa as well, like the cost of labor is lower.

So there's just a lot more people around than you might expect if you showed up to one in America where, you know, the biggest cost is, is the people in support.

So there's a lot of support there. But I could imagine that if they were all aligned and, you know, trying to improve

everyone's brain function, there might be a different menu, you know, being served.

There might be different ways in which they encourage the different, people there to connect with each other. And one of the most exciting things that I've seen is that I know that there is interest now for people who have read Dale Partizans book, The End of Alzheimer's, or people who have been made aware of your work and others.

There's a real emphasis now on trying to think if these kind of ideas could make it into places where they haven't in, in senior living facilities and memory care and Medicare Advantage and, you know, even as far up as, like the dementia leader's in a state by state in America.

So I'm excited that it's like, this is an idea whose time has come and that some of these ideas that have been spoken about previously, you know, this is the fourth one of these summits.

And I think uniquely, what we have here is a moment where this could actually change rapidly. And that's because the knowledge is incorporated in a way that can be shared, and used, which is unique.

Yeah. And I can, I can only imagine, you know, all of those people who are such compassionate caregivers at the senior living facilities. And what a different experience it would be like for them if the people they're caring for could actually have improvement, instead of just the steady decline that we've come to expect from from our conventional care interventions like that, that would be transformative for that community of people as well.

Well, one of the things that that I've come to understand, and I'm sure you understand better than I do, is just that, I think if you're listening to this, probably, you understand even the most is is what it takes energetically to be in service of a family member who's struggling with this.

And so, you know, I think that having having the ability to see things moving in a, in a different direction is extremely inspiring. And, I'd love to be able to give that gift to as many people as possible.

Yeah. Me too. That's a wonderful aspiration. What else do you think we should share with our viewers today? Yeah, I think I think the most important thing is to take it in from my perspective, is to take an inventory of the support systems that the person in question has.

So, you know, spouse, close family, family and friends, what are the communities that support the patients? I mean, even just having 1 or 2 things every week that someone does with other people and that that thing is healthy in nature.

So many of the traditions and culture that we have in America is built around when we're isolated, coming together, but coming together with unhealthy, unhealthy behaviors.

And so I think that if we can, for every patient that that is in line for this to be able to identify, you know, some, some opportunities for healthy connection that are regular, that one can give a break to people who are caring or can be part of that process.

But two can reinforce some of these healthy behaviors. And over the whole summit, you're going to hear about not just the healthy things that everyone can do to take care of us, but also some of the common root causes that drive a gut drive, Alzheimer's and cognitive decline, and anything that is done together with other people that is in service of modulating those areas will be valuable for everyone involved and extremely helpful.

Yeah. And I think too, that that brings up that that piece of bringing families together or bringing, you know, support people together, that opportunity to see, like you've talked to me about before, like, you know, your grandmother, your dad, and knowing that you have things that you can be doing to help change the path that you might be on biologically just from what you've inherited from your family lineage in terms of risk.

Yeah. Well, that's, you know, a lot of a lot is made of that kind of conversation with regard to, let's say, trauma. Right. That's a popular way of discussing, you know, sparing the lineage or changing the lineage of your family and

that there's a lot of conversation about that in the sort of psycho spiritual ways.

But like, here is an actual practical way of reducing the chance of an actual, disease state, that may run in the family through genetic reasons or may through, you know, through other reasons, other environmental drivers.

But yeah, it's it's amazing to be here at 44 knowing that the, the function of whether or not my brain is moving in the direction of Alzheimer's or not, is under my control at this moment.

And I would say I actually, since I got back from South Africa two months ago, and now I've come a year later and sort of seen, this is this is like there's elements of this.

It's really sad and, and hard to deal with. And hard to hard to manage. You may not, even from my perspective, to live on the other side of the world or to realize, like, I can't do everything that I want to do for my father because of real limitations that exist in in my life and his life and his ability to move around.

Is is sad because and that sadness has driven me to the next level of my, my physical health, you know, and my muscle creation and my desire to get up in the morning and get after it.

And so I think there's a very practical moment where it's it's exciting to clear the lineage of these kind of conversations, because I also see an interesting side note is that when I first came down to Cape Town to see my dad, who was then 86, the other person who came down from England was his twin brother and his twin brother, booked his own car, booked his own hotel, zipped around Cape Town like it was, you know, all the time.

And they actually also have a sister who's in her 90s who is also at that, like, I'll call the house now.

Family lineage, prevention, and closing remarks

She's out with friends. She just did this or did that. And so you start to see that, like these choices over a lifetime compound and some of its choices, some of it's not.

But these things compound and you really feel it between, you know, 80 and 90 if you're lucky enough to get there. And so I feel compelled to take care of myself, to show my kids what it looks like to take care of themselves.

And I recognize part of the reason why it's been hard for me to take care of myself is I didn't see my father doing it. In fact, one story that I'm never told before is that I remember the one memory I have my dad, well, he played tennis and golf, but I don't really see those as like that.

That's not really fitness, but I can remember being in a in a call with him when I was this, be with him in America. And a friend of ours, a friend of his was sort of like a bodybuilder.

And there was something that I took from that conversation that bodybuilding was not aspirational or being like that was not that was not a cool journey.

To go on like that was not a way to go. And certainly that was not part of the British culture at that point. This was in the 80s anyway, and I don't know, to whatever degree, but I think it just sat in my mind that like going to the gym and pumping weight, whatever was a thing that other people did, but not me.

You know, it took some of these moments to be like, hey, I'm not going out like that. Like I'm going to do it. The science has changed. This is actually extremely healthy.

Gaining muscle is a, you know, core of an organ of longevity. And so I've had to like, overcome some of my own, those sort of trauma lineages as a result to have like information that I processed from my dad's opinion about things and come face to face with his, you know, with the reality of his situation.

And that's been a strong motivator for me. Yeah. And those ideas can change so much over time. You know, as

you mentioned. Right. Like the science has changed and, you know, using weights to gain strength doesn't necessarily have to look like the bodybuilding days of the, of the 80s.

And so it's just all about the perspective about these things that, that we need to do to help keep our bodies healthy. And now, you know, we didn't know before that all of those things had such a profound impact on cognitive health.

We really kind of thought this was something that just happened to you and that you didn't really have any control over it. And now that we know that that's completely untrue and there's so much that we can do that dramatically alters whether or not we end up on that path.

That's really empowering. I think. Super powering. Yeah, I feel very empowered by it. I feel connected to it. And I'm now fully engaged in this topic, in my work life, in my home life, in my lineage, work with my kids.

You know, this is just what I'm living and breathing, and I'm really grateful for it, because it'll take this sort of attention over a long period of time to transform the way we do it, and to come right back to the beginning where you're talking about these other doctors not getting it.

We really need a large scale transformation. And that's why I'm excited to do this summit when, you know, maybe a lot of this material has been covered before, but what we have ahead of ourselves with true an era, you know, is a way that potentially the the standard of care could change.

And that to me is an accelerant that is worth fighting for. Yeah, it really is. It really is. Well, I can't thank you enough for joining me today, for being so open and vulnerable in sharing your dad's story.

I know it's been a very emotional journey, and I just really appreciate you being here and sharing the wisdom that you've gained from this experience and then how that's helped us to create this movement of acceleration to get this work to more people.

I would love for people to have an opportunity to learn more about the work that you've done, the work that you're doing, how how can they find out more about you?

The best place is probably James Mass Goal.com. My website I have a list of the different projects that I involved in. You can see the two books that I've written.

I do different types of speaking and yeah, I would love the opportunity if, you know, places that I could speak where we could get the word out about this, I'd love to hear from you.

And you can find all about that at jamesmaskellcom. Wonderful. Well, thank you again. And thank all of you, our viewers, for joining us on the summit today.

If you've enjoyed today's conversation, which I know that you have, then I welcome you to join us in some of our other presentations so you can learn more about the amazing capacity that we have to reverse cognitive decline.

Thanks for joining us.