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### Defining the Various Aspects of Dementia

#### Dr. McDonough:

Dementia is one of the most common health problems in this country, and although a great deal of research is being done, we certainly are far from any answer; but understanding dementia, dealing with it as a family member and looking at it from a professional standpoint is very important. And, of course, as primary care providers, many of the people in this audience have patients who are dealing with dementia in one form or the other.

Hi, I'm Dr. Brian McDonough, and welcome to Primary Care Today on ReachMD. My guest today is Dr. Tia Powell. She is the Dr. Shoshanah Trachtenberg Frackman Chair in Biomedical Ethics and Director of Montefiore Einstein Center for Bioethics, Professor of Epidemiology and Psychiatry at the Albert Einstein College of Medicine, also the author of Dementia Reimagined. Welcome to the program.

#### Dr. Powell:

Thank you, pleasure to be here.

#### Dr. McDonough:

My first question, Dr. Powell, is that when we talk about dementia, your area of interest and your focus and why? What got you involved?

#### Dr. Powell:

Well, unfortunately, in my case, as is true with so many of us, dementia is in my family. Both my mother and her mother had dementia and in a sense died of dementia, so I definitely feel like I'm kind of in the crosshairs there. I don't know what my genetic risk is, but I can see what my family history is, and that's enough for me to feel that not only is this such a common illness across the country, but I think it's coming pretty close to home, too. So, that is certainly the kind of information that makes one sit up and pay attention, so it's gotten my attention on dementia, I must say.

#### Dr. McDonough:

And what has your understanding been of what families can do and what others can do to help in the struggles? You've lived through it yourself, obviously.

#### Dr. Powell:

Yeah. Well, I think there's a lot we can do, and I'd like to be able to get us to think about dementia in something of a different way. As you know, there are more than 5 million people with dementia in the US, and along with those 5 million people with dementia, there are about 15 million caregivers, so this is something that affects an incredible number of people. We don't have a cure. I personally don't think we're likely to get one in time for the baby-boomers because our brains are already doing what they're going to do, but just because there's no cure doesn't mean there's no care. There actually are some really great home-based, evidenced-based interventions that people can do. Unfortunately, they're not as widely available as they should be, but there are some good people working on this, really kind of training caregivers, thinking about how we can keep people safely at home longer, which is what most people say they want to do, but there is some very interesting work going on about what we need to do.

#### Dr. McDonough:

Tell me about a few of the things—because I think you're right. I think we're trying to make progress, but there is a belief that it might be a long-term impact of lifestyle or just the genes that lead to dementia, right?

#### Dr. Powell:

Well, all those things probably make a difference. A disease that you get in your 70s or 80s, even if there is a genetic component—and

there probably is even for late-onset dementia—the mileage, the way you live your life definitely comes into it too, and so there are things that we know about. Interestingly, the cohorts of people in their 70s and 80s show a lower percentage today than they used to of people getting dementia, so that's great. And people think that's probably due to better cardiovascular care, watching out for your blood pressure, avoiding strokes, not smoking, leading a more fit lifestyle, a healthier diet with more fruits and vegetables. All of that is great. Unfortunately, it's not a prevention. You can do all those good things and still get dementia. And actually, that was true of my mother and her mother. They were both way ahead of time, incredibly fit, never smoked a cigarette in their lives, drank moderately, healthy diet, lots of education, all the good things they did, and they got dementia anyway. So, you should do those things, and it may slow things down, but it's unfortunately not a preventive measure.

So, what we can do, though, is we can think about, well, we make get dementia, some of us. Certainly, what can we do to slow it down through a healthy life, but what can we do to have a better life with dementia? And there are actually some great people studying that. There's a wonderful program out of Johns Hopkins called The Mind at Home. The VA has a program called VA Reach. There's a wonderful program called the NYU Caregiver Program. And all of those things really look at how we can keep people safely at home, sort of what it takes, what kinds of assessment you need of the environment. Is the home safe? What kinds of things should the person do more of, do less of? How can we help family members with the things that really make it hard to keep somebody at home, and things that are dangerous like driving or cooking or managing all the medications that older people are off and on, or even handling money. I think a lot of caregivers are doing the best they can, but they don't have the education they need, and these interventions have really looked at helping the caregivers. And when you do that well, it actually helps people stay out of the nursing home for up to a year for the NYU Caregiver Program. They did a study that was across the state of Minnesota, and it basically saved Minnesota close to a billion dollars—or I guess that was the projection of what it would have saved if they had expanded it to the whole state. So, helping people stay out of the nursing home saves money and it makes people happier, especially if you can do it safely and give them good care at home. So, those are some of the things that people are doing. There is a lot more that I think we need to do.

Dr. McDonough:

Tell me about your book *Dementia Reimagined*. What's your focus?

Dr. Powell:

So, there are a couple different aspects. It certainly tells a bit of the personal story of my family and why I got interested in this, but also, because I'm a physician, it really looks at the history of dementia research. Not that long ago people hadn't really focused on dementia as a separate disease, so it's really only from the beginning of the 20th Century that people really began to think about it as an illness as opposed to just, "Oh well, that's something that old people do." So, it looks at the discovery of dementia, if you will, and the research around it, coming, unfortunately, to the regrettable conclusion that there is... I don't personally think there is likely to be a cure in the immediate future, partly because we've had so many disappointments in the big studies involving reducing amyloid. And the amyloid story is a very complicated one. It's clearly not a good thing having huge build-ups of amyloid, but it's also true that there are people who have a lot of amyloid and are older and are fine. They don't demonstrate the symptoms of dementia, and really, no one has a perfect explanation of why that's true. So, it's clear that amyloid does not absolutely equal dementia, although that's the way we've defined it. That's the way we've defined Alzheimer's disease. If you have excess amyloid, you have Alzheimer's disease, except you don't necessarily have the symptoms of it. So, for me personally, if I don't have the symptoms, I'm okay with that.

Dr. McDonough:

Right. What about vascular, mini strokes, those sorts of things?

Dr. Powell:

Well, there are lots of different kinds of dementia; you're absolutely right. And in fact, a lot of people, probably the majority of people with dementia probably have a contribution from more than factor, so they may qualify for Alzheimer's by having excess amyloid; they may also have mini strokes. Certainly, there are a lot of people with vascular issues, small strokes, big strokes, all kinds of things. I think in years past we didn't pay as much attention as we do now to concussions, to traumatic brain injury. So, I think in a long life, there could be multiple factors that contribute to that. And then there are all of the social determinates too in terms of education and how much you've really been able to use your brain, how intellectually active you are, how connected to other people in your community. There are just a lot of different contributing factors, and probably different ones matter more in different decades of our life as we get older in terms of what might be sort of weighing on a person at a particular point and making dementia symptoms kind of flourish. So, it seems to be a very complicated picture.

I think we've gotten better in that many more people now at least get the diagnosis of dementia, but most of those people are told they have Alzheimer's disease, and we don't actually really know that's true. Probably a lot of them have some kind of combination, and how you are going to beat a combination of things that come at your brain from all different angles—man, that's going to be tough. That's not a single pill. So, I think we're going to have to really get even more... There are lots of smart people working on this, but I think we're

going to need even more and a lot more successes than we've had if we're really going to push off dementia even further and make it not affect us until we're even much older than it does now.

Dr. McDonough:

Now, you mentioned, obviously, because of family history you are at somewhat greater risk. What about the rate of dementia running in families? Where are we with those statistics?

Dr. Powell:

Well, I'm not sure about the rate running in families. I mean, there certainly are different genetic components of different kinds of dementia, so there are a number of early-onset dementias that really do have a strong genetic component. So, there are a couple of very well studied, very isolated, actually quite small groups of people in Columbia or in different mountainous regions where there is a powerful genetic component. Because those are isolated groups, there is an early-onset dominant gene, and if you've got it, you are very, very likely to get dementia, get it early and get it very seriously, have a very rapid course and a rapid demise, so that is full-on genetic, and it doesn't look like in that particularly kind of early-onset dementia—which fortunately is quite rare, it's way less than 1% of the cases of dementia—that lifestyle, that's not really going to help you. You've got a very, very heavy genetic load. But with the more...

An intermediate category maybe is something like frontotemporal dementia, which we probably failed to recognize in a lot of people in a lot of people in earlier generations. That has a pretty early onset too and a fairly rapid decline, and that too looks like there may be some heavy family carriage there.

But for the more common, older-onset dementia that's at 65 or later, there are a couple of different genetic risk factors. There are actually quite a few different ones. The most common, probably, is apoE epsilon 4, and if you have a single gene, that's going to increase your risk several-fold, and if you have 2 copies of the gene, it's going to increase your risk I think as much as 15 times above the general population. But here's the interesting story about that. So, you've got to watch out; you don't want to have the apoE 4 gene. It's still true that most of the people who have Alzheimer's dementia don't have that gene, so I'm not sure why you would need to get it tested. If you have a positive test, you know you're at risk, but my guess is you've already seen your family and know you have a family history. If you have a negative test, it doesn't really tell you anything, because most of the people who have dementia are negative for apoE 4. So, the genes here with the older-onset dementia are very complicated. There is definitely some risk, but it's a risk factor. It's not a done deal. It's not like that early-onset, really, really sinister form of dementia that gets you early and hits you really hard.

Dr. McDonough:

My guest is Dr. Tia Powell. She is from the Montefiore Health System, and she has written the book *Dementia Reimagined*. Just time for one more question, and that would be for those of us who have patients and plenty of patients who have dementia in their families. Are there specific lifestyle changes or things you recommend that people can do when they're young and throughout their life to try to at least theoretically reduce the risk?

Dr. Powell:

Right. Well, I actually like a phrase that I think the CDC popularized a few years ago, which is, "What's good for your heart is good for your head." So, having a healthy lifestyle, absolutely don't smoke, think about a diet with more fruits and vegetables. I'm not extreme on diet issues. I don't think you have to be a vegan, but I think if you can dial up healthy food like fruits and vegetables and dial down the fried foods, dial down the salt and all of that, that will help you. I think using your brain is great. I mean, we really think you can still build connections in your brain even as you get older, so keep doing things that are intellectually stimulating for you. I don't really care if it's a crossword puzzle. I don't care what it is. But as long as you are using that brain, that's certainly good for you. It might be formal education. It might be building things, doing something else, whatever you like. Staying fit, really walking, running, whatever makes you happy, that really just does seem to be just a great thing for you; and actually, it's good for your mood too, so even if it doesn't prevent dementia, it will probably make you happier in the short-term because it does provide you with a nice bunch of endorphins when you exercise—so I think just the main common sense things. Stay connected with other people that you care about, stay active both physically and mentally, keep away from the bad things: cigarettes, don't drink in excess. Probably a lot of things that your mom could have told you: eat your vegetables, go for a walk, stay active. A lot of that actually makes sense.

Dr. McDonough:

Tia Powell, I want to thank you for joining us on Primary Care Today on ReachMD. I really appreciate your time. Also, I recommend the book *Dementia Reimagined* if it's something you want to pick up at the store or Amazon or all the places you can buy books. Thanks again, Dr. Powell.

Dr. Powell:

Thank you so much. Thank you.

Dr. McDonough:

This is Dr. Brian McDonough. If you missed any of this discussion, please visit [ReachMD.com/PrimaryCareToday](https://ReachMD.com/PrimaryCareToday). You can download the podcast, you can learn more about the series. Thank you for listening and being part of the knowledge.