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Caregiver Thought Leader Interview: Neelum Aggarwal • July 8, 2015

#### EDITOR'S PEN

Gary Barg, Editor-in-Chief

## Caregiver Thought Leader Interview: Neelum Aggarwal

*Dr. Neelum Aggarwal is a population health neurologist and clinical researcher in the field of longevity and aging. She's a co-leader of NIA funded Rush Alzheimer's Disease Center clinical core in Chicago, director of the Cardio Cognitive Clinic at the Rush Heart Center for Women, and an associate professor in the Department of Neurological Sciences at Rush University Medical Center. She maintains an active clinical practice as senior attending neurologist at the Rush Alzheimer's Disease Center, conducts multiple large-scale trials in Alzheimer's disease, and has performed over 25 hundred home visits in Chicago's racially diverse neighborhoods for aging and dementia studies conducted through the center. She was recently appointed as the first chief diversity officer for the American Medical Women's Association, the oldest physician medical organization in the US. And she's responsible for defining AMWA's national diversity and inclusion objectives, and enhancing diversity of AMWA's leadership team and resource groups*

**Gary:** What does it mean when our loved ones receive an Alzheimer's disease diagnosis?

**Neelum:** It means that there is a neurodegenerative process happening in the brain and this process is ongoing. It's the process that right now we don't have a cure to stop and by use of medications we try to slow. One area I want to mention is that when you say Alzheimer's disease, it means that already the diagnosis of dementia was given. This is an important point. You have to have a dementia diagnosis first, before you say you have Alzheimer's disease

dementia.

**Gary:** We've been working hard over the past 20 years to help family caregivers understand the value proposition of clinical trials and, in fact, to demystify the phrase "clinical trials." So now that I have you, what is a clinical trial and why is it important for caregivers to know about them?

**Neelum:** Well, I'm really appreciative that you asked that question because it is important to discuss. If someone comes in a trial, they may come in for a new medication that is not on the market as of yet. The key thing about a trial is that it's a regulated type of a study, which means there is a certain protocol or a schedule when people come into a clinic and are asked questions by research assistants. The doctor who's conducting the trial will be there to do an exam. There may be blood taken. There may be imaging, brain imaging done. These are really important things to consider, especially in Alzheimer's disease. It should be part of an Alzheimer's treatment plan to discuss trials in the future for a participant and a family member.

**Gary:** Another thing to realize is there's not a single drug out there that we take that hasn't gone through a clinical trial.

**Neelum:** Absolutely! Sometimes people say, "Well, how do these drugs come on the market?" or "Why did this drug come on the market?" If we don't have people participating in trials, we really can't push the field forward with new drugs coming out. The other thing that I want to mention is that we do not have enough minorities participating in trials. We need to have their participation to understand whether the drugs are working the same in different ethnic groups.

**Gary:** This is actually a very interesting time in [Alzheimer's research](#). What are some of the latest developments in the field that you find exciting?

**Neelum:** For many years, people essentially had to have a diagnosis of Alzheimer's disease made at autopsy. Now with neuroimaging, we're able to see changes in the brain occurring years ahead of time. We're actually able to see this occurring in people who are living and people who may be at risk for developing the disease. This is really changing how we look at the disease, how we talk about the disease. And it has allowed us to start thinking about prevention. I think that is tremendously exciting because it gives people hope.

**Gary:** What are [Don'tforgetAlzheimers.com](#) or [Alzheimerschicago.com](#)?

**Neelum:** These are two websites that are really important to go onto and to look, see, and learn about information that is being shared here. Check them

frequently because they will have new information being posted.

**Gary:** We also find that the family caregiver plays an incredible role when a loved one with cognitive disorders is in a clinical trial. What role do you see the family caregivers playing when your patients come in to your practice?

**Neelum:** The family caregiver, and this can't be stated enough, is so integral to what I do every day. Not only are they taking care of somebody at home 24/7 every day, but they are also observing what is going on. And in the past, we haven't really paid that much attention to their burden and how they're feeling. There is depression in caregivers. There is also elation in caregivers. They feel such a sense of satisfaction in really providing care. But I'm always sensitive to the burnout that there is with caregivers in providing care all the time. I tell all my caregivers that you have to take care of yourself in order to take care of a loved one. If you don't take care of yourself, you cannot take care of your father, your mother, your husband, etc. So please take care of yourself and what should we do to help you take care of yourself? Frankly, a lot of times, it's just rest.

**Gary:** It's job one for any caregivers to learn how to care for themselves.

**Neelum:** Exactly!

**Gary:** For the longest time, people were concerned about stepping up and getting early detection of Alzheimer's disease because the thought was, what would it help to know? But now it does make sense to have early detection. Why is that important and what are the signs we should be looking for in ourselves and our loved ones?

**Neelum:** We're really heading into the prevention role with this disease. I may see some changes that I think could be the early signs of the disease, such as short term memory loss or getting confused in directions. Sometimes those are the very early signs of a memory issue that should be looked at. The goal is, do we rule this in or do we rule this out?

**Gary:** Have you found anything that we can do or change in our lifestyle that could help prevent the disease?

**Neelum:** We're finding a lot of links between heart health and brain health. And that's one of the reasons why I started the cardio cognitive clinic at our Heart Center for Women, where the women were complaining of memory issues associated with heart disease. In addition to that is eating right and physical activity, which, by the way, walking is the best activity that you can do.

You also have to get your stress under control. This is so important for brain health. With uncontrolled or negative stress, the brain really takes a hit in the sense that you don't think as clearly as you should. And not only that, it feeds into changes in sleep and mood.

**Gary:** What would be the one most important piece of advice you'd have to offer a family caregiver?

**Neelum:** My concern with caregivers is they feel isolated. They feel out of mainstream. Many of them really say that they just feel alone out there with what they're doing. And sometimes it's just because of sheer exhaustion. But, a lot of times, people don't ask enough questions. You need to know the latest information: Is there a trial available? Is there something that I can get involved with? This is one of the nice benefits of a trial. When people come into any type of trial for Alzheimer's disease, they get attention. Caregivers have often said to me that their stress levels have gone down because they're getting information at each trial visit. I'm encouraging caregivers to keep asking and learning about the disease, but to also consider participating in a trial.

The other thing I'm going to ask caregivers to do is always keep yourself front and center. I can't stress this enough. You are integral to everything. And if you keep yourself healthy as best as you can and ask people for help when you need it, your health will be positively affected and it's going to help your loved one. And as a caregiver, you have to sleep and you have to eat. That's something that people forget about and it's really important for your own ability to function. You need to do both and both are going to impact your cognitive health.

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