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Caregiver Thought Leader Interview: Megan Carnarius • August 17, 2015

## EDITOR'S PEN

Gary Barg, Editor-in-Chief

### Caregiver Thought Leader Interview: Megan Carnarius

*Alzheimer's specialist Megan Carnarius, RN, is known for her warmly human touch in working with people with dementia and those who love them. Trained in Europe and the United States, she has international perspective and 25 years' experience in designing and running memory care settings.*

**Gary Barg:** You are the author of *A Deeper Perspective* and I love that title. What made you decide to write the book?

**Megan Carnarius:** I felt there was so much life between diagnosis and the person departing from this earth and a lot of focus was being addressed on the losses and trying to adjust to those changes and how does one feel and cope with that. I felt like there wasn't as much emphasis on the deeper aspects of this process and what people can learn by being a caregiver to someone who has dementia. Including, what the person with dementia may be processing or working through in their life. I wanted to find out a way to address that, but also really still be addressing the things that are practical that people need to know.

**Gary Barg:** I love the connection between practicality and spirituality. That is caregiving in a nutshell.

**Megan Carnarius:** Definitely. It is an amazing thing. You are standing by someone and they are changing and you are doing the best you can to support

them and you have to stay light-footed. There are all kinds of things that you notice about yourself while you are trying to give the support, things that the person brings out in you. Sometimes those things are hard to look at and sometimes there are really loving amazing things that access. It is a big learning experience I think to be a caregiver for a loved one.

**Gary Barg:** Well along those lines what would you say a caregiver can specifically learn from reading your book?

**Megan Carnarius:** When someone has a dementia illness they tend to move backward through time losing the last thing that they had developed. So, for example, functioning as an adult in the world you drive a car, you manage your finances, you multi-task and you have things you are interested in. What families experience with a loved one sometimes in that early stage is almost a flattening of the personality where they are not able to multi-task in the same way. I have identified that as the loss of adult learning. When you think about the things that as the caregiver you would ask, how would I step in and help without being patronizing, Figuring out ways to companion, figuring out ways to work together on things instead of *I'm doing this to you*. There is a finesse and attention that needs to be paid at that stage because the person's sense of themselves often is struggling the most at that point. They realize there is something different. They may not acknowledge it. They may not have insight, but an aspect of themselves is going to be fighting really hard to maintain their independence and autonomy and it is very challenging for others to step in. We are looking at it as a very intense life review and things are going to be more heightened before they let it go. And they don't want to let these things go.

**Gary Barg:** Let's talk a little bit more about life review. That is a great concept. How does it work with Alzheimer's?

**Megan Carnarius:** There is a part of the brain called the hippocampus where when you have an experience, it transforms into long-term memory using that part of the brain. And in Alzheimer's in particular that is the part that is damaged first. So people can be very present and appropriate, but they can't transform the experience to long-term memory. So they might not be able to report back to you about what they had for breakfast or what they did yesterday. In the early stages, they can remember things way back with great detail. As the disease progresses, their short term memory becomes more expanded. For a caregiver, they have to figure out where this person is really living in their life review. Where are they right now? And I sometimes ask the question: *Who is the President?* And if someone tells me Roosevelt or Kennedy, I have an idea of how old they were when that person was the President. Or if they are approaching me and saying, "I am looking for my children." And I say that they are at work right now and they look at me in horror telling me that they need to

be in school, I know that we are really far back.

There is also a potential to try to resolve things in someone while they are revisiting those years. An example is that person looking for their mother and I will ask is there anything I can help you with – they say my mother is very, very ill. I need to find her. And I talk to the doctor and I find out her mother was really ill when she was in her 40's and she couldn't get to her mother to give her care because of her own family life. Here is something this elder is trying to resolve.

All of us do this as we age, but when you have dementia it makes it that much more challenging and also that much more visceral because the person is harvesting the long-term memory which is what is available to them. So it can be a very rich and important time if we can respond to it in the right way and help them resolve that.

**Gary Barg:** That brings me to one of my favorite parts in the book is your use of storytelling to highlight different aspects. Do you have a favorite story you would like to share?

**Megan Carnarius:** One funny thing was there was an elder who always took walks in our two courtyards. One was a good size and she could do loops and enjoy that and then she would go over to the side. There was a day the sprinklers came on at the wrong time. And at first she was shocked and she tried to run away from the sprinkler but invariably she ran into the next one. So a couple of staff people ran out to try to direct her. And then she noticed that we were pursuing her. So she intentionally ran into every sprinkler. So because we were following her we ran into them too. When we came back inside everybody was laughing. There was no old or young or ill or well. We were just having a really funny moment and we were all soaking wet. I just think it is really important to have moments like that in caregiving.

**Gary Barg:** What would the one most important piece of advice be that you would like to share with caregivers?

**Megan Carnarius:** I think that they have to acknowledge their feelings about what is going on and get support and help around these feelings. There is this self-sacrifice and merging that goes on when you are really caring for someone in an intense way. That immersion causes some self-forgetfulness. You have to shift from that acute, adrenaline reaction to things happening around you to start really planning to keep yourself full. How can I keep myself full but I can still be giving from my reserves. And if I spend all my reserves there won't be anything left. It's what do you do with a gas stove. You turn the burner down.

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