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Caregiver Thought Leader Interview with Camille Claiborne • July 13, 2016

EDITOR'S PEN

Gary Barg, Editor-in-Chief

Caregiver Thought Leader Interview: Camille Claiborne, APRN, PhD

*A nationally recognized expert in nursing, thanatology and leadership. She is the author of two books: *Dying in God's Hands*, which is designed to comfort the dying and their loved ones, and *Purses & Shoes For Sale*, which focuses on caring for elderly parents.*

Gary Barg: Tell me about the new book, *Purses and Shoes for Sale*. I love the title.

Camille Claiborne: Thank you. The title came from taking care of my mom and dad for the last ten years during their aging, my mom's ultimate death and my dad's journey with Alzheimer's. As a nurse, I was learning things I didn't know about as I cared for my parents in the community and I thought it would be a good idea to journal and write down things that we're happening to our family to help other families who were also caring for their parents. I thought it should be a story, a resource guide and some information to help others navigate through this really tough yet beautiful time in one's life.

Gary Barg: I think when you say 'purse and shoes for sale,' any caregiver gets what that means.

Camille Claiborne: Yes. It was my mom really that came up with that as she talked about the simplicity of life and death and her beliefs in a Christian afterlife. That it really boils down to simple

things, you live, you're going to die, let's do it well and then pray for an afterlife if that's what you believe in. She's the one who came up with the talk.

Gary Barg: What have you heard from caregivers about your two books?

Camille Claiborne: Well, wonderful things. I've done multiple workshops in the last few months. and I think caregivers really want to be creative, be supported by other caregivers and talk to other caregivers. Like, how did you do it, what happens if they can't take care of themselves at home, or what if they can't drive? How do you talk about that, or how do you get all of your siblings on the same page or are there resources for veterans? I just thought we are really an enormous group of men and women trying to take care of other men and women, and it's pretty cool to be a membership called caregiver.

Gary Barg: What is thanatology and why does a caregiver need to know about it?

Camille Claiborne: Thanatology is the study of death and dying. I was always interested in this in my four decades as a nurse. Often it was a surprise conversation either after a long beautiful life and/or sometimes a very tragic ending of life, but it was the subject that people were often afraid to talk about. It's very painful. It's tough to talk about death and dying. And so I studied during my graduate education how people prepare for death and interviewed hospice patients, so I could begin to uncover some dialogue that I might be able to give to patients, families, and community members to start the conversation. So we can better plan when possible for a peaceful death and for quality at the end of life.

Gary Barg: Can you help us demystify what it means when we hear the words hospice and palliative care?

Camille Claiborne: It is very scary to think about one's own mortality but it is a fact of life that we're all going to die. It's a matter of when. I believe that what hospice does is bring a team of multidisciplinary, talented individuals to a person that is troubled with how to deal with it to help them not only learn how to take care of their person, but also help the person who is facing a terminal illness to be able to live their life to the fullest whether it be weeks, months, or years, or sometimes days. To leave that legacy or say things they may never have the chance to say.

I've been volunteering for hospice for 18 years in the not-for-profit in our community to help the conversation be easier. It's always difficult, and I know it'll always be difficult because it deals with the pain and suffering of another, but I think if we continue to put it out there as something we can help with, we

can demystify the conversation. I'm not sure if we can ever demystify death and dying, but we can begin to at least help people feel there's someone there to help support them.

Gary Barg: So many times, our doctors really try so hard to help our loved ones, but sometimes the best help that they can give is to suggest hospice and palliative care, and a lot of times I think they see that as a failure. How do we, as caregivers, communicate to our doctor that it's okay to consider hospice?

Camille Claiborne: That is absolutely the diamond question. My belief is that talking about palliative care and hospice as options for anybody in their life before they even get there. It's very difficult to talk about it when you're stressed of an ICU or maybe two days trying to grasp what kind of illness or diagnosis you just received. I believe that, by talking about it now when I might be healthy or you might be healthy or feel healthy and at least begin to articulate to those we love what our wishes are. It lightens the load. I think the conversations at any age that at least get people's wishes out and begin to help physicians not be the first one to bring the conversation up at a difficult time. They can be in force to try and follow someone's wishes when they do get sick.

Gary Barg: Tell me some more about both your books, *Dying in God's Hands* and *Purses and Shoes for Sale*. What is it that you want a caregiver to get from either one, and how do we find them?

Camille Claiborne: The first one, *Dying in God's Hands*, was actual interviews with patients that were in active dying. They were hospice patients. They welcomed me into their home and told me about their experience and life and end of life. They talked about what they did to leave a legacy and to communicate their pain and suffering but also to celebrate their lives with their families as they went through a difficult time. In that work, I looked at how people do prepare, how families and hospice members support them and what recommendations could make make that a peaceful time in someone's life as they face difficulties.

I just continued to do that work after the book came out in 2007 doing hospice workshops or having conversations about death and dying. They're not always the ones that people want to have because it has the D word in it, but I did get many caregivers and nurses and physicians and social workers and hospice folks to continue to have that dialogue. My goal was to help one person, and I know through feedback that that has occurred. You can get the book through AcadianHouse.com, which I believe you had put it on your website. It's coming currently, so they can click on that button and both books are available. When I worked on *Purses and Shoes for Sale*, it was an evolution of our family's ten-year journey to date. We're still on a journey with dad. He's ninety three and a

half.

Gary Barg: Wow.

Camille Claiborne: The ten-year journey to kind of take apart what happens when someone goes from independence to dependence. What happens when they can't take care of themselves at home? What resources are available to bring to the home? What happens with falls and medications, and how do we take care of the financial needs of those that are home? If they can't live at home, what is assisted living, what is skilled care and what is nursing care? What happens with hospitalization? So I just began to document the possible stages. So I did a few things in that book that took my nursing experience and my family experience and then also what I had learned from death and dying to take it a little step further. I wanted to put all of these conversations out and talk about how difficult it may be to take care of your parents but what a joyful, beautiful gift that God called me to do to continue to take care of my dad.

Now I'm doing work on Alzheimer's. There's a little bit about it in the book, but I want to do more work on that to help children and spouses that are taking care of partner or friend or a parent that has Alzheimer's.

Gary Barg: If you only had one piece of advice to share with the family caregiver, your most important piece of advice, what would that be?

Camille Claiborne: That is a great question. I think the most important thing I would tell them is, while you may look for what can I do and how can I do it better, they should always remember their presence is the most important thing on this journey. When we're totally present and open with somebody in need, we can be open to the learning experience and find out what is death for them. Not necessarily what we know in the book because sometimes we learn something and then our loved one takes a different road, or their illness becomes a little bit darker, particularly with Alzheimer's and dementia. So to know our presence alone and acknowledging people for being present, that's what I do. I tell caregivers all the time, you are doing the work of the world. Don't stop because it's so important.

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