Discussion Guide



*In Stroke's Shadow: My Caregiver Story*Kyle Ruffin

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Caregiving

Summary

When Kyle left her marketing position at one of Philadelphia's iconic media outlets to start her own consulting business, she thought she was finally in complete control of her life. She had no idea things were about to take a sudden and dramatic turn. A few short months after launching her dream, Paula, Kyle's youthful, vibrant and active mother suffered the first of three strokes. Within the space of 24 hours, stroke catapulted mother and daughter into a whole new world and a relationship for which neither was prepared. "In Stroke's Shadow" is Kyle's story.

"In Stroke's Shadow" explores a journey so many are, will be or have been on. This poignant memoir spurs readers to reflect on their own experience and release anxieties familiar to all who find themselves on this road. It is an unapologetic look at the struggles, conflicting family expectations, exhausting frustrations, self-doubt and the internal tug-of-war that shapes every caregiver's reality.

Kyle's story offers a release valve to caregivers — particularly caregivers of color. It acknowledges the overwhelming the hardships while encouraging often underappreciated family warriors to occasionally put themselves first so their healing can begin.

Questions

- 1. Kyle's sudden introduction to caregiving wasn't something she was prepared for. Were you prepared when you got the call? How did your life change from what you expected it to be? Were you caught off guard by the challenges you faced interacting with the medical establishment?
- 2. Kyle talks about differences between her and her mother's cultural and generational expectations. Were their differences in how you and your loved-one believed the crisis should be managed? Were there trust issues that you had to deal with? For example, did your loved one harbor deep-seated mistrust of the medical system? Or did your loved one trust that you were handling their needs well?
- 3. Kyle spoke of having a diverse group of people helping her. Who was there to support you in this time of great need? How did they support you? When people offered to help, did you give them an opportunity to, or did you think asking for their help would be too much of an imposition?

- 4. Kyle talked about the known and unknown relationships and underlying family dynamics that were always in the room with her and her mother? She also talked at length about regretting how she managed the deaths of her father and sister. What family history is at work under the surface influencing your feelings and approach to caring for your loved one? What was your relationship with your loved one like before you became their caregiver?
- 5. Besides the medical aspect of caregiving, Kyle talked about other areas that she was now forced to manage for her mother, personal finances and keeping another household were among the biggest. Are you dealing with things like that for your loved one? How and who is part of making and following through on these kinds of decisions. Are you and your siblings amicably sharing the load or are there problems?
- 6. Kyle sought help from therapists to better understand her relationship with her mother and how it was making caregiving difficult. Have you sought therapy or other support to get to the bottom of your concerns and issues around caregiving?
- 7. Kyle's husband's negative feelings were revealed during their trip to Canada when it became clear he had enough of his mother-in-law interrupting their time together. How is caregiving effecting your personal relationships with your spouse, significant other, children, friends, extended family, and/or the people with whom you work?
- 8. Kyle struggled with having the "end of life" conversation with her mother because she knew her mother wouldn't receive it well. When they filled out the POLST form together, it was obvious that her mother didn't think she might die. Have you been able to discuss end of life wishes with your loved one or with others who'd be affected by their death? If not, why?
- 9. There were situations when Kyle got very angry with her mother and said or did things she later regretted. Has that ever happened to you? How did you handle it?
- 10. Kyle admitted that she never thought stroke would bring her and her mother closer together, but indeed it did. Has that been a silver-lining for you and your loved one?
- 11. Family secrets, bad behavior, true feelings all made their way to the surface during Kyle's caregiving journey. Has any of that happened to you and how did it make you feel?
- 12. Kyle had more than a few uncomfortable run-ins with staff of facilities her mother was in over the three years. Did you experience times when staff wasn't living up to your expectations? Have you ever felt you weren't being taken seriously?
- 13. After her mother's second stroke, Kyle had to make the very difficult decision to leave her mother in a nursing facility permanently and sell her home. Have you had to make that decision? How did you handle it?
- 14. Do you feel your story was represented here? Can you relate to Kyle's journey?
- 15. Of all the information presented in "*In Stroke's Shadow*," what has stayed with you the most? What did you learn from hearing Kyle's story?