

Identity Theft: Rediscovering Ourselves After Stroke
By Debra E. Meyerson, PhD with Danny Zuckerman

Book Group Discussion Questions for the General Audience

We're so glad you've chosen to read *Identity Theft: Rediscovering Ourselves after Stroke*, by Debra E. Meyerson, PhD with Danny Zuckerman. We hope you find the book insightful and informative about the importance of the emotional journey to rebuild identity following stroke (or any life changing illness or trauma).

If you're reading with a group or are just interested in deeper personal reflection, we've prepared some questions that may serve as a guide. While you may certainly go through all of the questions below, you might want to select a subset most relevant to you or your group, and which fit your needs, interests, and time constraints. Depending on the group, about six questions seem to work well for a one hour discussion. The questions are arranged roughly in order of the book chapters, so they may also be divided across multiple sessions, if preferred.

As you review these questions, keep in mind that individual identities are dynamic and multiple. Throughout our materials, even though we may refer to identity in the singular form, the plural is always implied to encompass both the multiple facets of an individual's identity and how these evolve over time.

If you have any feedback after reading and discussing *Identity Theft*, please do share it with us at programs@strokeonward.org.

1. In the first chapter of *Identity Theft*, “A Slow Fall off a Cliff,” Debra shares the experience of her stroke, both from her own and from her family’s perspective. In particular, she highlights the uncertainty - the medical team was able to diagnose her stroke, but unable to say why it happened, what the outcome would be, or even what recovery would look like.
 - a. Did anything surprise you about Debra’s experience?
 - b. Have you or has anyone close to you experienced stroke or another illness/trauma that had an uncertain outcome?
 - i. If so, how was it similar to or different from Debra’s experience?
 - c. How do you think this uncertainty impacts survivors and their supporters, especially when the uncertainty about recovery potential may last months and even years?

2. Identity is a central theme of *Identity Theft*. In Chapter 3, “A Teacher without Words,” Debra defines identity as a “network of meanings we hold in multiple contexts,” such as work, family, and community. She discusses the ways in which trauma disrupts our understanding of who we are, and shifts the question from “Who am I now?” to “Who do I want to be now?”
 - a. What does “identity” mean to you?
 - b. How do you describe who you are to others?
 - c. Would a friend, colleague, or family member describe you differently?
 - d. Has your identity changed over time?
 - e. Have you ever felt there was a gap between who you are and who you want to be?

3. In Chapter 4, “Moving Forward,” Debra redefines “recovery” not as regaining what was lost, but as, “rebuilding a new life of meaning and

joy.” She frames this in terms of Dr. Kuluski’s “narrative reconstruction,” in which people can frame their experiences in more positive or negative ways, and consciously choose a personal narrative characterized by a loss of hope (Chaos Narrative), or by a focus on recovery (Restitution Narrative), or even a belief that illness is an opportunity for growth (Quest Narrative).

- a. What do you think of Debra’s discussion of a forward-looking approach to poststroke recovery?
 - b. Do you feel agency over your own narrative in your life?
 - c. What barriers do you experience?
 - i. Have you employed any strategies described in the book to help you overcome them?
4. The second section of the book, “What It’s Really Like, Outside and Inside,” deals with different aspects of stroke recovery, and uses the stories of several stroke survivors to demonstrate the variety of experiences people have with things like therapy, caregiving, and social interactions.
- a. Were there particular stories that resonated with you?
 - b. What aspects of recovery have you found surprising?
 - c. What aspects of recovery have you found familiar?
5. In Chapter 6, “Let Me Talk!,” Debra discusses aphasia, which affects the ability to communicate for more than two million Americans and about a third of all stroke survivors. It can be particularly difficult to reconstruct identity and relationships while struggling with aphasia. As one stroke survivor noted, “When I’m home alone, I don’t have aphasia.”
- a. What do you think of the ways in which stroke survivors in this chapter adapted to living with aphasia?

- c. Have you experienced changes to family roles that are chosen (like marriage)?
 - d. Have you experienced changes to family roles that are imposed (like an illness or injury)?
 - i. If so, did imposed changes feel the same or different than those that were chosen?
 - ii. Why?
8. Chapter 9 also discusses caregiving. Debra notes that stroke recovery, “often requires the entire family to recover, adjust, and accept support themselves.” Burnout is common among carepartners, as is depression. Culture can also influence how people feel about asking for or receiving help.
- a. Do you have any experience with caregiving?
 - i. If so, what was the experience like for you?
 - b. What do you think your culture or upbringing dictates about dependency and asking for (or offering) help?
 - c. Do you agree with Debra’s conclusion that asking for help can in fact be a sign of strength?
 - i. Why?
 - d. Do any of the carepartner experiences relayed in *Identity Theft* resonate with you?
 - i. If so, which one(s) and why?
9. Chapters 11 and 12, “People are Social Animals” and “How the World Responds,” both deal with how survivors interact with the people around them, and how those people interact with survivors. Debra notes both the importance of social interaction for wellbeing and the frustrations of re-asserting one’s identity in a world not built for people with disabilities.

- a. How can friends support one another in the event of sudden disability?
 - b. What role does social interaction play in your life and how might stroke or another traumatic event impact that?
 - c. Did this book impact your understanding of people with disabilities?
- 10.** Chapter 14, "Careers and Callings" describes how the motivation and meaning behind a career can differ for each individual. Sally Maitlis studied professional musicians after stroke as exemplars of those who see work as a calling. She found that, "for anyone whose occupation provides a master status—a role around which other identities are organized—a trauma that prevents them from doing their work is likely to have a significant effect on their self-understanding. Typically, these individuals see their profession not simply as what they do, but as who they are."
- a. What role does career play in your life?
 - b. Would you categorize yourself or perhaps someone you know well as having a "calling"?
 - c. If forced to transition away from that role by a stroke or other illness, what impacts would this have?
- 11.** Chapters 15 and 16, "Dealing with Financial Strain" and "Advocating in the U.S. Medical System," deal with some of the practical, logistical challenges stroke survivors face. Even with insurance, care for stroke recovery may be extraordinarily costly, and navigating the healthcare system to find the right care and secure ways to pay for it can be a full time job on its own.
- a. What do you think of the healthcare system's current practice to treat stroke within an "acute care" and short term framework?

- f.** Knowing that it is possible for one's identity to shift or be changed in a moment, if you could intentionally and voluntarily change one thing about your life today, what would it be?



Rebuilding Identity and Rewarding Lives

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Book Group Discussion for the General Audience

Chapters 20 & 21: Supplemental Questions

1. "In Chapter 20, Debra and Steve discuss their experiences with 'cycles of grief' following Debra's stroke. How do you think acknowledging and working through these cycles can impact the recovery process for survivors and their carepartners? Have you or someone you know experienced a similar emotional journey?"
2. "Chapter 21 highlights the importance of creating a more holistic and effective stroke system of care. What changes do you think are most needed in the current healthcare system to better support stroke survivors and their carepartners? How can individuals and organizations work together to drive these changes?"