

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

Book Group Discussion Questions for Healthcare Professionals

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 reading and especially discussing the book with colleagues will build awareness and inspire change in professional practice patterns to spotlight the importance of the emotional journey to rebuild survivor identity following stroke (or any life changing illness or trauma.)

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 or recommendations 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. What other analogies or images have you heard used by survivors and carepartners to describe their experience?
 - c. Early after onset, do you attempt to paint an idealistic or realistic picture for survivors?
 - d. How do you typically respond to questions from survivors and carepartners about the future?

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. As you think about your own identity, what are some of the underlying drivers that shape your identity?
 - c. Has your identity changed over time?
 - d. Have you ever felt there was a gap between who you are and who you want to be?
 - e. How would you feel if your identity as you know it was taken from you by a stroke or other trauma/illness?
 - f. How and when do you think the identity theft that impacts survivors should be addressed by healthcare professionals?

- 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.** Do you think Debra’s discussion of a forward-looking approach to post-stroke recovery is typical of survivors?
 - b.** What barriers to this orientation do you typically experience in your work with survivors?

 - i.** Have you suggested using any strategies described in the book to help survivors overcome them?
 - ii.** What other strategies do you recommend?
 - c.** When a survivor and carepartner do not agree about the risk/benefit of attempting a new goal, how do you typically approach this discussion if asked to participate?"

- 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.** Do the stories shared echo what you have heard from survivors and their carepartners?
 - b.** If you could add a story to the book from your own experience as a practitioner, what would it be?

- c. As a healthcare professional, when you need support, do you have access to adequate resources?

- 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. Are you familiar with the Life Participation Approach to Aphasia (LPAA)?
 - b. What techniques and practices do you utilize when working with survivors with aphasia?
 - c. What additional techniques and practices could you use to facilitate communication?
 - d. What resources do you provide to carepartners for their use with survivors?

- 6. Chapter 7, “Grief,” discusses the ways in which we mourn what is lost, whether that be a person or a way of living. The grieving process and the emotional journey of stroke survivors may be as difficult as physical recovery, yet fewer resources are available and it receives far less attention. In this chapter, Debra advocates for the inclusion of psychological support for survivors, while noting that there are many barriers to care, including finding stroke-and especially aphasia-experienced therapists, and the financial ability to pay for them.
 - a. How is the process of recovering from a stroke similar to the bereavement process?
 - b. What role do you believe you and others on the medical team need to play in identifying (and educating survivors and carepartners to

- identify) depression, grief, and other mental health recovery needs following stroke?
- c.** Is grief a topic that should be discussed with all survivors as a standard touchpoint(s) in the recovery process?
 - d.** What types of emotional support and resources do you believe help survivors and their carepartners the most?
- 7.** In Chapter 9, “Stroke is a Family Illness,” Debra discusses the impact her stroke had on her entire family, including how they have redefined their roles and relationships.
- a.** Do you see a difference between the recovery progress of survivors who have a strong family (or other) support network and those who do not?
 - b.** What experiences or insights can you share about how stroke impacts a family beyond the stroke survivor?
 - c.** What guidance do you typically provide a survivor and their significant other about navigating intimacy during recovery?
 - d.** What resources or advice do you share with patients who may lack a strong support network?
- 8.** Chapter 9 also discusses caregiving. Debra notes 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.** In your experience, do most carepartners make self-care a priority?
 - i.** Are they typically willing to ask for and receive help?
 - b.** Do you see a difference in carepartner behaviors based on gender or culture and upbringing?

- c. Do you agree with Debra’s conclusion that asking for help can in fact be a sign of strength?
 - d. What additional advice or resources do you typically provide carepartners?

- 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. Do you discuss the importance and challenges of social re-entry with survivors and their families?
 - b. Do you share techniques or sample statements they might use to help them acknowledge their stroke and encourage respectful and compassionate interactions with others?
 - c. What do you believe holds survivors back from social interaction, and what additional resources or tools might you recommend to assist them to reintegrate faster and/or find new communities for support?

- 10. 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. How do you feel the US healthcare system impacts patient equity in terms of access to care and related outcomes?
 - b. What might the impact be of treating stroke recovery more like diabetes or other chronic conditions where patient education and support is built into the system?

c. What system change(s) do you think would most help all stroke survivors?

- 11.** Debra and other survivors must ultimately try to find a balance between the determination to recover as much capability as possible and an acceptance of limitations that may be ongoing. Even in the face of these limitations, some survivors report being happier post-stroke as they become living examples of the Japanese art of kintsugi, where broken pottery parts are mended with silver and gold.
- a. When and how do you recommend survivors be engaged about the need to be both determined to recover and accept stroke impacts that may prove to be long term?
 - b. What characteristics or circumstances seem to contribute to a survivor finding happiness?
 - c. What strategies or resources do you recommend to survivors who struggle to achieve or maintain a positive outlook?
- 12.** Debra ends the final chapter with, “we still get to choose where we steer our path next, who we become now... for those of us lucky enough to be survivors, stroke does not steal our future or who we get to become next.”
- a. How has reading this book impacted your understanding of survivor identity?
 - b. After reading this book, how will you alter your treatment approach to better serve the emotional needs of stroke survivors?
 - c. Do you think the emotional recovery needs of survivors are adequately addressed in current medical education and curriculum?
 - d. What one thing will you change about your own interactions with stroke survivors and carepartners beginning today?

- e. How will you advocate or better address the needs of survivors and their supporters in the future?