Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Book Group Discussion Questions for Carepartners

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 peers or perhaps friends and family will build awareness of and support for carepartner needs. We want to spotlight the importance of the emotional journey to rebuild both survivor and carepartner identities 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 be divided across multiple sessions easily. For those interested in a more in depth, chapter by chapter discussion, please see additional materials available via Stroke Onward's website.

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. Debra and Steve utilize the term “carepartners” to define their post-stroke relationship; they intentionally do not define Steve as a caregiver. This choice has helped them both to feel more comfortable with their roles, and removes the implication that Steve is always the giver while Debra only receives care. They are on this journey together.
    - **a.** What term do you use when describing your role relative to your survivor?
    - **b.** What term does your survivor use to describe your role?
    - **c.** What do you think about the term, “carepartner”?

2. Debra describes how after her stroke, “Without much information, my family had to figure out how to react.” (p. 13). As carepartners, there is a lot of information processing, risk assessment, and decision making that typically must happen very quickly.
    - **a.** What has this experience been like for you?
        - **i.** Did you initially have friends/family to serve as sounding board(s) or did you feel alone?
    - **b.** How supported did you feel throughout the decision process?
        - **i.** Did you comfort others or were you comforted?
    - **c.** Did you take control of the situation, feel helpless, or both?
    - **d.** Did you feel equipped to make the best decisions for your survivor, and for yourself as carepartner?
    - **e.** What level of detail did you share with your survivor at the time?
    - **f.** Did your communication style with your survivor change before and after their stroke, especially when discussing serious matters?
        - **i.** If so, how?
    - **g.** Would you do or communicate anything differently knowing what you know today?

3. 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 ongoing 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?
        - **i.** How was your experience similar and/or different?
    - **b.** What analogies or images would you use to describe your experience?
    - **c.** Do you share these analogies or images with your survivor?
    - **d.** Do you tend to paint an idealistic or realistic picture of the stroke experience?
    - **e.** How do you typically respond to your survivor’s questions about the future?
    - **f.** How do you respond to questions from other people about the future?
    - **g.** Is it difficult to balance staying positive for your survivor with other needs and feelings you may have as carepartner?

4. Identity is a central theme of *Identity Theft*. In Chapter 3, “A Teacher without Words,” Debra describes 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?” This impact is true for both survivors and carepartners.
    - **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.** How has becoming a carepartner influenced your identity?
   - **e.** Has being a carepartner subsumed or overpowered other aspects of your identity?
   - **f.** Have you ever felt there was a gap between who you are and who you want to be?

5. 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, consciously choosing 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.** Which narrative do you naturally tend to embrace?
   - **b.** Do you ever fluctuate between the three narratives, or tend to combine them?
   - **c.** Is your dominant narrative (as carepartner) the same as your survivor's narrative?
   - **d.** Is it important that they be the same?
      - **i.** Why or why not?
   - **e.** Have you encountered barriers to embracing the Quest Narrative?
      - **i.** If so have you utilized any strategies described in the book or other ones to overcome them?
   - **f.** Can you envision embracing as a growth opportunity a recovery that also includes ongoing limitations for your survivor?
      - **i.** For yourself?

6. 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 your own experience as a carepartner?
  - **i.** Does one particular story resonate strongly?
- **b.** What is the most challenging or difficult encounter you had as a carepartner?
  - **i.** Why was it so hard?
- **c.** What is the most inspiring or uplifting encounter you had as a carepartner?
  - **i.** Why was it so positive?
- **d.** If you could add another story to the book from your own experience, what would it be?

7. 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.** Is your survivor living with aphasia? If so, please continue to the additional questions below.
- **b.** How does your survivor’s aphasia affect your ability to communicate and interact?
- **c.** How have your survivor’s other relationships changed as a result of aphasia?
- **d.** Have your own relationships changed as a result of your survivor’s aphasia?
- **e.** What techniques and practices have you found effective when working to communicate with your survivor?
- **f.** What communication training have you and your survivor received?

  - **g.** What barriers do you continue to encounter?
  - **h.** Are there ways that additional training or resources might help?
  - **i.** Are you familiar with the Life Participation Approach to Aphasia (LPAA)?

8. 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 the physical recovery, yet fewer resources are available for meaningful emotional recovery and it receives far less attention. This may be equally or perhaps even more true for their carepartners.
  - **a.** How is the process of recovering from a stroke similar to the grieving process outlined by Kübler-Ross that includes five stages: denial, anger, bargaining, depression and acceptance (not necessarily in order)?
  - **b.** What education and resources were provided to you on this topic by your medical team or others?
  - **c.** What steps of the process do you feel you and your survivor have gone through since experiencing a stroke?
  - **d.** Where do you feel you are now in the process?
  - **e.** Did you find any stages to be harder, or last longer, than others?
  - **f.** Have you experienced certain stages more than once?
    - **i.** If so, what do you think has contributed to these cycles?
  - **g.** Is your survivor now in the same place as you?
    - **i.** If not, how does this affect your communication and relationship?

9. In Chapter 9, “Stroke is a Family Illness,” Debra discusses the impact her stroke had on her entire family, including how family members redefined their roles and relationships. These impacts were felt most immediately and significantly by her husband Steve as Debra’s main carepartner.

- **a.** How has stroke impacted your family and/or others close to your survivor?
- **b.** What additional roles and responsibilities did you assume in the aftermath of your survivor's stroke?
- **c.** Have these roles changed over time and are they continuing to shift?
- **d.** Which roles are you the most/least comfortable with?
- **e.** Are there roles that are currently needed that you are unable to fill?
- **f.** How involved are other family members and/or friends?
- **g.** Are there any roles that could be assigned to others, especially over time?
- **h.** Are there any relationship roles from your pre-stroke life that were abandoned, that you miss and possibly could be brought back with or without adaptation?

10. Debra also notes in Chapter 9 that stroke, "often requires the entire family to recover, adjust, and accept support themselves." Burnout is common among carepartners, as is depression. Culture, gender, and other factors can also influence how people feel about asking for or receiving help.

- **a.** Have the broad impacts of stroke and any resultant role changes and needs been openly discussed with family and close friends?
- **b.** How easy or hard is it to ask for and receive help?
- **c.** Do you feel pressure to participate as a carepartner in a certain way due to gender, cultural expectations, or other factors?
- **d.** Have you found ways to allow self-care to also be a priority?
- **e.** Do you agree with Debra's conclusion that asking for help can in fact be a sign of strength?
- **f.** What steps did you take to ensure your own mental health and well-being, either early on or later in the journey?
    - **i.** Were these enough?

   g. If needed, have you considered using professional resources to help understand and navigate changes in family dynamics, carepartner responsibilities, and associated emotions?
   h. What advice would you offer to a new carepartner or family experiencing a stroke's aftermath?

11. 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 other 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. Did your survivor find social interaction difficult following their stroke?
      i. Did you?
      ii. Have these feelings changed over time?
   b. What do you feel might make it difficult for your survivor to maintain or rebuild a social life?
   c. Have you been able to maintain or rebuild your own social life following your survivor’s stroke?
   d. Have any foundational relationships in your personal or professional life been broken by the stroke or the realities of post- stroke life for you as carepartner?
   e. Have the things you value in social interactions as an individual or together with your survivor changed since the stroke?
   f. Have you sought or been able to find community among other carepartners?

12. Chapters 15 and 16, “Dealing with Financial Strain” and “Advocating in the U.S. Medical System,” deal with some of the practical and logistical challenges stroke survivors and their carepartners 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 impact did your survivor's stroke have on your family's financial status and future?
- **b.** In addition to career and income impacts, how challenging has it been to navigate the financial aspects of stroke recovery?
- **c.** Do you feel that there are potential paths to recovery and therapy that are inaccessible to your survivor due to financial or logistical reasons?
- **d.** Has your survivor inquired about the specifics of any financial burdens on you?
- **e.** Have you discussed any hardships openly with your survivor?
    - **i.** If so, did you find these discussions helpful to you and/or your survivor?
- **f.** Have you explored public and private sources of financial assistance or considered avenues like clinical trials that may help?
- **g.** If you're still experiencing financial hardship, are there additional steps you can take to find resources and support?

13. Debra and other survivors must ultimately seek a balance between the determination to recover as much capability as possible and the 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.** Would you use kintsugi or a different metaphor to describe your survivor's post-stroke life?
    - **i.** Your own life as a carepartner?

- **b.** Has your survivor been able to reclaim meaningful pieces of their old life or have they primarily had to craft new ones?
  - **i.** Have you?
- **c.** How challenging has it been for your survivor to find a balance between a determination to push for improvements and acceptance of any limitations?
- **d.** Has finding this balance also been a challenge for you?
- **e.** Are you and your survivor generally in agreement on if/when balance has been achieved?
- **f.** How do you and your survivor approach the anniversary of the stroke?

14. 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." This is also true for carepartners.

- **a.** How has reading this book impacted your understanding of carepartner identity?
- **b.** Were there any stories that resonate strongly with you?
  - **i.** If so, which ones and why?
- **c.** After reading this book, will you alter anything about how you approach your role as carepartner?