Rebuilding Identity and Rewarding Lives

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

Introduction

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's stroke exposes her to a community built around navigating post-stroke life. She notices "similar dynamics in other communities, as well—colleagues struggling with the loss of a loved one, survivors recovering from brain injuries, and even just friends facing the realities of older age." (p. 3)
    - **a.** Think about these communities.
        - **i.** How are they similar?
        - **ii.** How might they differ?
    - **b.** What communities do you currently participate in?
    - **c.** Have you had opportunities to be an active participant in a carepartner group?
        - **i.** If not, have there been any obstacles to your joining a carepartner group?
        - **ii.** If so, has being part of a carepartner group helped you?
            - **1.** Why or why not?

- **d.** How might you go about finding or strengthening your communities of support?
- **e.** Has your survivor had opportunities to be an active participant in a survivor group?
    - **i.** If not, are there local or virtual options for your survivor to participate?
    - **ii.** If so, have these activities been helpful?
        - **1.** Why or why not?
- **f.** Do you and your survivor belong to any of the same support groups?
    - **i.** Why or why not?
    - **ii.** Would you like to participate in a group together?

3. Debra states, "I found numerous resources to help me understand my journey to recover physically, but there was a profound lack of guidance when I faced the emotional challenge of rebuilding my sense of self." (p.3)

- **a.** Do you agree or disagree with this statement?
    - **i.** Why?
- **b.** Did any healthcare professional(s) discuss your survivor's mental health recovery at any point with you?
    - **i.** If so, was this discussion focused on acute symptoms, potential longer term mental health counseling needs, or both?
- **c.** Was the emotional challenge of rebuilding identity and a healthy new sense of self addressed? If so,
    - **i.** By whom?
    - **ii.** When?
    - **iii.** Was this input helpful?
        - **1.** Why or why not?
- **d.** Did any healthcare professional(s) discuss your own mental health needs as a new carepartner with you at any point?
    - **i.** If so, was this discussion focused on acute or potential longer term

mental health counseling needs, or both?

- **e.** Was the emotional challenge of rebuilding identity and a healthy new sense of self addressed? If so,
    - **i.** By whom?
    - **ii.** When?
    - **iii.** Was this input helpful?
        - **1.** Why or why not?
- **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?

4. Debra states, "A vital part of my rebuilding process has been acknowledging, and sometimes even celebrating, my identity as a stroke survivor." (p 6)

- **a.** How do you and your survivor mark the anniversary of the stroke?
- **b.** Has the way you acknowledge the stroke changed over time?

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Chapter 1: A Slow Fall Off a Cliff

1. 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 was this experience like for you during the acute post stroke recovery phase?
     - **i.** Did you take control of the situation? Feel helpless? Both?
     - **ii.** Did you feel equipped to make the best decisions for your survivor and yourself as carepartner?
   - **b.** Did you have friends/family to serve as sounding board(s), accessible medical professionals, or did you feel alone?
   - **c.** How supported did you feel throughout the decision process?
   - **d.** Did you comfort others or were you comforted?
   - **e.** Did your communication style with your survivor change before and after their stroke, especially when discussing the stroke and other serious matters?
     - **i.** If so, how?
     - **ii.** What level of medical/recovery detail did you initially discuss with your survivor?
     - **iii.** What level of medical/recovery detail do you discuss with your survivor now?
     - **iv.** Would you do or communicate anything differently knowing what you know today?
   - **f.** As recovery progressed, how did the support you initially experienced change over time?

2. Debra and her husband describe the night of her stroke as, "a slow-

motion fall off a cliff." (p. 16)

- **a.** Would you describe your survivor's stroke experience in the same way?
  - **i.** Why or why not?
  - **ii.** Are there different analogies or images you've used? (Share a picture if you like.)
- **b.** Would you describe your own experience as a carepartner in the same way?
  - **i.** Why or why not?
  - **ii.** Are there different analogies or images you've used? (Share a picture if you like.)
- **c.** Has the suddenness of stroke and the uncertainty surrounding recovery added to the emotionally difficult nature of dealing with the stroke for you and others in your support network?
  - **i.** Why or why not?

3. While Debra is in the ICU during her first two months of recovery, she writes "I found myself grasping for connections to the outside world." (p. 22)

- **a.** Were you surprised Debra wanted to hear about the outside world while in the hospital?
  - **i.** Why or why not?
  - **ii.** Was this also true for your survivor?
- **b.** What feelings surfaced when you and your survivor would discuss updates about the outside world?
- **c.** Some have shared that the ICU experience makes the outside world "shrink as it is difficult to focus on anything beyond immediate needs." Was this your experience?

Chapter 2: Everything Can Fail

1. Debra describes Steve's return to work as, "a much-needed return to some normalcy for him." (p. 24)
   a. Are routines important to you as a carepartner?
      i. Why or why not?
   b. Have you been able or required to return to your old "normal"?
      i. What has this transition been like for you?
      ii. What has this transition been like for your survivor?
      iii. What obstacles or benefits do you see?
   c. How has the uncertainty surrounding stroke recovery affected you and your ability to re-engage with the important people and activities in your life?
   d. Did you or your survivor have a sense at any point that a return to "normal" might not be possible?
      i. What did that feel like?

2. Debra states, "In the early period after stroke, many of us struggle to process our new condition." (p.32)
   a. What was the early phase of recovery like for you and your survivor?
   b. What were the predominant emotions that you felt?
   c. Did you or your survivor have significant concerns about the risk of recurrent stroke?

3. Debra writes that, "Drawing on what I care most about, whether family or fitness or advocacy—or for many, religion or a cause—is not only a source for motivation but a way to guide my actions." (p. 45)
   a. How would you describe the things you cared most about before your survivor's stroke?

   - **i.** What personal values did these fulfill within you?

b. Have the things you care most about or your priorities changed since your survivor’s stroke?

   - **i.** If so, how would you describe your key values now?

c. What other ways can you honor or express these values in your life? For example, if you needed to reduce your commitment to a career you enjoyed, are there other ways that you can create a similar sense of purpose?

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Chapter 3: A Teacher Without Words

1. How we each define personal identity can be complex and change over time. "Identity is multiple, dynamic, relationship-based, and interpretive. We are constantly evolving, and so are our identities, both informing our choices in life and being informed by them." (p. 34) Consider your own identity:
   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. How has your identity changed over time?
   d. Share an example of an identity change that you chose, e.g. marriage, and one that was imposed upon you, e.g. death of a parent or loss of a job.
      i. How did you feel after these different types of changes?
      ii. How do these feelings compare to how you felt after your survivor's stroke?

2. How we interface with the world matters. As Debra describes, "When there is no clash between how we think of ourselves and how we present ourselves in various situations, we are happier and more resilient. If there is a disparity, we become stressed or even distressed." (p. 35)
   a. How do you introduce yourself today when meeting a new group?
   b. Has the way you introduce yourself changed since your survivor's stroke?
      i. Do you typically include your carepartner responsibilities?
      ii. Why or why not?
   c. Does how you introduce yourself vary from group to group?

3. Debra describes identity as, “a network of meanings we hold in multiple contexts,” such as work, family, and community. (p. 39). 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 their carepartners.
    - **a.** How has becoming a carepartner influenced your identity?
    - **b.** Has being a carepartner overtaken other aspects of your identity?
    - **c.** Have you ever felt there was a gap between who you are and who you want to be?

4. Debra refers to Maslow’s Hierarchy of Needs as, “a tool for thinking about my problem. Maslow’s hierarchy gave me a way to understand my desires, frustrations, and challenges—both physical and emotional.” (p. 40)
    - **a.** Since your survivor’s stroke, has their position as described on Maslow’s hierarchical pyramid changed?
        - **i.** If so, how?
        - **ii.** How has this impacted you?
    - **b.** Since your survivor’s stroke, has your position as described on Maslow’s hierarchical pyramid changed?
        - **i.** If so, how?
    - **c.** If you and/or your survivor feel like your position on the hierarchy has downshifted, what kind of support would you need to be able to return to your prior position?
    - **d.** How have your and your survivor’s transitions along Maslow’s hierarchy impacted your communications, relationship, and journey together?

Chapter 4: Moving Forward

1. When Debra agrees to speak at a Pacific Stroke Association event four years after her stroke, she surprises herself by, "saying a sentence I hadn't prepared at all: 'I am a happier person now.'" (p. 43)
   - **a.** Were you surprised to read that Debra considered herself a happier person at the time of the speech?
   - **b.** Has your survivor mentioned aspects of life that feel more positive after their stroke?
   - **c.** Do you observe any other positive changes in/for your survivor?
   - **d.** Is there anything in your own life or your family's life that is more positive after your survivor's stroke?

2. Stroke survivor and activist Julia Fox Garrison describes herself as a "survivor," explaining "There's a victim, and there's a survivor, and it's a true choice." (p. 46) Debra notes that this choice goes far beyond semantics.
   - **a.** How does Garrison's decision to identify herself as a "survivor" affect her recovery and her outlook?
   - **b.** Do you feel your survivor naturally identifies as a survivor?
     - **i.** If not, how might you support them to do so?
   - **c.** Do you naturally identify as a carepartner?
     - **i.** If this continues to be a struggle for you, will you seek resources for support?
   - **d.** Has your survivor ever expressed feeling invisible because of their disabilities?
     - **i.** If so, how might you help your survivor understand the importance of advocating for themselves?
   - **e.** Have you observed your survivor being disregarded or disrespected

because of their disabilities?
    - **i.** How did your survivor respond?
    - **ii.** How did you respond
- **f.** Does your survivor's communication skills or aphasia impact their ability to advocate for themselves?
    - **i.** If so, how?
    - **ii.** How does this impact you?

3. Health researchers Dr. Kuluski and her colleagues refer to the process of "narrative reconstruction", with the three common frames of mind in chronic illness being the Chaos Narrative (loss of hope), the Restitution Narrative (focus on recovery) and the Quest Narrative (belief that illness is an opportunity for growth). (pg. 44)
- **a.** As a care partner, which narrative do you tend to embrace?
    - **i.** Why?
- **b.** Do you fluctuate between the three narratives, or tend to combine them?
    - **i.** Has there been a natural transition between them over time?
- **c.** Is your dominant narrative as carepartner the same as your survivor's narrative?
    - **i.** Is it important that they be the same?
    - **ii.** Why or why not?
- **d.** 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?
- **e.** Can you envision fully embracing as a growth opportunity a recovery that also includes ongoing limitations for your survivor?

4. Debra states, "reminding myself to look ahead and focus on progressive small wins in the future rather than comparisons to the past is key to continued progress." (p.45)

   - **a.** When do you find your stroke survivor or yourself most likely to look backwards?
      - **i.** What is it about those situations that compels you to focus on the past?
   - **b.** Do you think focusing on the past is harmful?
      - **i.** Why or why not?
   - **c.** What are some examples of when looking forward to an event or goal helped you or your survivor post-stroke?
   - **d.** Are there events or small/big goals in your and your survivor's life that you're looking forward to now?
   - **e.** Have you or could you use meaningful goals centered around future events to motivate yourself or your survivor?

5. Debra states, "Growth that is exciting and even novel—like letting go of my career stress—makes my progress more than just clawing back what I've lost, it's deeply rewarding." (p. 46)
   - **a.** Many of the people profiled in the book state that they found new interests and developed new insights about themselves because of their stroke experience. Did any examples stand out to you?
      - **i.** Which ones and why?
   - **b.** Has your survivor developed any new interests during their recovery?
      - **i.** Do you feel that they would have developed these if they hadn't had a stroke?
   - **c.** Have you developed any new interests?
      - **i.** Are any of these interests ones that you might not have developed if you were not a carepartner?
   - **d.** Do you have the resources—time, financial, emotional, and someone to help with your survivor's care—to explore new interests?
      - **i.** Are there other barriers that currently prevent you from exploring new interests?

   - **e.** Are there additional ways you might help yourself and/or your survivor overcome any barriers and explore new interests?

6. Debra states that, "Recovery does not have to mean rebuilding exactly what was lost." (p. 49)

   - **a.** Do you agree with this statement?
      - **i.** Why or why not?
   - **b.** How well do you understand the deeper values that motivate you?
   - **c.** How well do you understand the deeper values that motivate your survivor?
   - **d.** Do you or can you envision embracing recovery as a growth opportunity if it also includes ongoing limitations for your survivor?
      - **i.** Why or why not?
   - **e.** Do you or can you envision embracing your survivor's recovery as a growth opportunity if it also includes ongoing limitations for you?
      - **i.** Why or why not?

Chapter 5: The Grind of Therapy

1. Debra states that, "Because of the unpredictability, positive thinking is particularly important in stroke rehab." (p. 62)
    a. Has positive thinking helped your survivor make physical and/or mental health gains?
        i. Has it helped you?
    b. How do you support and comfort your survivor on the inevitable days when they are feeling less positive?
    c. How do you support and comfort yourself on the inevitable days when you or your survivor are feeling less positive?
    d. Is it difficult at times to balance staying positive for your survivor with other needs and feelings you may have as carepartner?
    e. Does your response to questions from other people about the future change if your survivor is or is not present?
        i. If so, how?

2. Orienting herself around Karl E. Weick's important concept of "small wins" enables Debra and others to "battle through the grind of therapy, not just in the first year but beyond." (p. 63)
    a. Discuss the concept of "small wins." Why are they so important to those in recovery?
    b. Are there any "small wins" that your survivor has achieved during their recovery that make your survivor or you particularly proud?
        i. Why?
    c. Have you had any "small wins" as a carepartner that make you particularly proud?
        i. Why?

3. During her rehabilitation, Debra and Steve adopt the motto “Sometimes you have to go slow to recover fast.” (p. 64)
    a. How is slowing down, which feels counterintuitive to Debra, something that will help speed up her progress?
    b. Do you feel this applies to your survivor’s recovery?
    c. Do you have a motto or mantra that you like to use to keep your survivor motivated and positive during their recovery?
        i. If so, what is it and how is it helpful
        ii. Has it changed over time?
    d. Do you have a motto or mantra that you like to use to keep yourself motivated and positive?
        i. If so, what is it and how is it helpful?
        ii. Has it changed over time?

4. Debra reinforces the notion that time for family, friends, and other activities is important to include alongside rehab. (p.64)
    a. Has your survivor been able to incorporate time for recreational and other activities into their life?
        i. If so, has this impacted you in any way?
    b. Have you been able to incorporate time for recreational and other activities into your own life?
        i. If so, is it enough?

5. In reference to the often shared belief that most recovery will take place within the first 12 months following stroke,
    a. Do you agree with this statement?
        i. Why or why not?
    b. Reflect on progress that your survivor has made so far during recovery; what examples can you share?
    c. Reflect on progress you have made as a carepartner during that time;

what examples can you share?

- **d.** If your survivor is at least 12 months post stroke, are you continuing to see progress?
- **e.** Is it helpful to your survivor to hold the belief that recovery can continue over an extended period of time?
  - **i.** Why or why not?
- **f.** Is it helpful to hold the belief that recovery can continue over an extended period of time?
  - **i.** Why or why not?

Chapter 6: Let Me Talk!

1. Debra writes, "My challenges are primarily expressive: an inability to communicate my thoughts, both speaking and writing. Far more than my limp or lost use of my right arm, substantially diminished speech and writing capability has altered my life the most." (p.68)
    - **a.** If your survivor has lost capabilities as a result of their stroke, what changes have impacted them the most?
    - **b.** If your survivor has lost capabilities as a result of their stroke, what changes have impacted you the most?
    - **c.** Have you been able to help your survivor thrive in new ways?
    - **d.** Have you been able to advise or guide others about how best to support your survivor to thrive?

2. 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.** Does your survivor experience aphasia?
        - **i.** If so, how does your survivor's aphasia affect their ability to communicate and your ability to interact?
    - **b.** Have your survivor's other relationships changed as a result of aphasia?
    - **c.** How have your own relationships changed as a result of your survivor's aphasia?
    - **d.** Are you familiar with the Life Participation Approach to Aphasia (LPAA)?
    - **e.** What techniques and practices do you utilize when working to communicate with your survivor?
    - **f.** What communication training have you received?
    - **g.** What barriers do you continue to have?

Chapter 7: Grief

1. Many counselors and therapists "compare the experience of stroke to bereavement" (p. 80) and the Kübler-Ross grief model can be used as a resource and framework to help stroke survivors through the grieving process.
    - **a.** How is the process of recovering from a stroke similar to the grieving process?
    - **b.** What stages of the emotional grief model do you feel you and your survivor have gone through since experiencing a stroke?
    - **c.** Where do you feel you are now in the process?
    - **d.** How did you, as the carepartner, feel watching your survivor experience various stages of grief?
    - **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 relationship and communication?
    - **h.** Were any tools shared in *Identity Theft* particularly helpful in accepting the emotional impact of your survivor's stroke?
    - **i.** Have you found other tools or techniques helpful that weren't discussed in the book?

2. Debra shares that, "clinical depression affects one out of three stroke survivors and it often goes undiagnosed" (p. 80)
    - **a.** What are the signs of clinical depression?
    - **b.** Are you familiar with symptoms of anxiety, post-traumatic stress or other potential mental health issues following stroke?
    - **c.** Have you seen signs of depression in yourself or your survivor since your survivor's stroke?
    - **d.** Debra notes that "many doctors as well as family members tend to

explain away depression as an understandable response." (p. 85) What's the effect of explaining away depression?

   - **e.** Have your survivor's emotional needs been properly met by the professionals with whom you have worked during their post-stroke care experience?
      - **i.** How has this affected you?
   - **f.** Have your own emotional needs been properly met by the professionals with whom you have worked during your post-stroke care experience?
   - **g.** What resources have you used for support along the emotional journey?
   - **h.** Have you found it challenging to find appropriate emotional support for your survivor or yourself?

3. In addition to some of the other coping strategies that Debra shares, she writes that she's "picked up meditation, which has helped me keep calm and reset my frame of mind when needed." (p. 86)

   - **a.** Have you or your survivor tried meditation?
      - **i.** If not, how might the practice impact your and your survivor's recovery?
   - **b.** Are there any other types of practices, like yoga or music, or apps that you find particularly helpful?

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Chapter 8: Lean On

1. Beyond your own prioritization of self-care as a carepartner, it's important to recognize that "supporters need support, too—encourage those in the 'outer rings' of your support network to help anyone who is closer in." (p. 101)
    - **a.** Who are the people in your own outer rings on whom you rely for support?
    - **b.** How does it feel for you to ask for help?
    - **c.** What has the response been from family members and friends if you have requested their help or support?
    - **d.** What makes it easier to ask for help?
    - **e.** Has your support network changed over time?
        - **i.** If so, how?
    - **f.** Do you have any unmet support needs at this time?
        - **i.** If so, can you think of any possible ways these needs might be met?

2. The question "How can I help?" may unwittingly add to a survivor's burden. Debra writes that making a specific care suggestion "both shows thoughtful support and saves them the energy and discomfort of making a response and finding things to ask for." (p. 97)
    - **a.** Can you think of concrete ways someone could help you or your survivor at this time? For example, providing you and your family with a meal? Helping clean your home or walk a pet?
    - **b.** How can you/someone share this list with your support network?
    - **c.** If your network lives far apart, are there meaningful ways that they can offer support from a distance?
    - **d.** How can you show gratitude to those who have helped you after your survivor's stroke?
3. Consider the questions "How are you doing?" and "How are you doing

today?"

- **a.** What is the difference between them?
- **b.** Why might a carepartner or a survivor prefer to be asked, "How are you doing today?"
    - **i.** Do you have a preference?
- **c.** How ARE you doing today?

4. Debra writes, "Immediately after my stroke, I avoided most social interactions, so even some close friends didn't see me for a while…some, either out of discomfort or an intentional desire to not treat me as just a stroke survivor, didn't even acknowledge the situation. This is isolating." (p.96)

- **a.** Is it important to you for people to acknowledge that you as a carepartner have gone through something life changing?
    - **i.** Why or why not?
- **b.** Is it important to you for people to acknowledge that your survivor has gone through something life changing?
    - **i.** Why or why not?
- **c.** Have you had people acknowledge your carepartner role or your survivor's stroke in ways that were particularly meaningful?
    - **i.** What made them stand out?
- **d.** Have you had people say something about your survivor's stroke or your carepartner role that you found upsetting?
    - **i.** If so, what was said and why was it upsetting or hurtful?
    - **ii.** Did you attempt to explain your reaction to the person in the moment or at another time?
- **e.** Can you think of several ways to help people understand the types of interactions that may be more helpful to you and your survivor?

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Chapter 9: Stroke Is a Family Illness

1. The chapter titled "Stroke is a Family Illness" (p. 102) begins with Sarah Zuckerman's "Chapel Talk." In it, she describes the lessons she learned about "going it alone."
    a. Discuss the chapter title. Do you agree with its assertion?
        i. Why or why not?
    b. Why do you think that Debra chose to include her daughter's speech in this chapter?
    c. How do you think your survivor's stroke impacted your family, friends, and community?
        i. Did reading Sarah's speech change your view in any way?
    d. Do you agree that asking for and accepting help from others can in fact be a sign of strength?
        i. Share your reasons.

2. In her chapel talk, Sarah Zuckerman describes her support network as "a net ready to catch me if I fell." (p. 104)
    a. How would you describe your survivor's support network?
        i. What about your own as a carepartner?
    b. How have these networks changed over time?
    c. How comfortable are you with asking for and accepting help?
    d. How have the people in your support network helped you and your survivor?
        i. Consider reaching out to your support network to let them know how appreciative you are to have them in your life.
    e. If you feel the need, how might you go about strengthening or finding new communities of support?

3. Gabrielle Kitzmuller and colleagues identified four common themes in families' post-stroke experiences: family as a life buoy, absent presence, broken foundations, and finding a new path forward. (p. 108-110)
    a. Which theme resonates the most with your circumstances right now?
    b. Has this changed over time?
    c. Did you as the carepartner feel like a life buoy for an extended period of time?
    d. If so, do you still consider yourself to be one?
        i. How does this make you feel?

4. Debra talks about the many roles Steve played in the immediate aftermath of her stroke: primary caregiver, healthcare advocate, emotional coach, motivator, financial manager, rehab equipment manager, etc. (p. 112)
    a. What current roles do you have in the aftermath of your survivor's stroke?
    b. Have these roles changed over time?
    c. Which roles are you most/least comfortable with?
    d. How involved are other family members and/or people close to your survivor?
    e. Have you had to take on new domestic roles in addition to your direct role as a carepartner?
    f. Are there any roles that could be assigned to others, especially over time?
    g. Are there roles that are currently needed that you are unable to fill?
    h. Are there any roles from your pre-stroke life that have been abandoned and are missed, that could possibly be brought back with or without adaptation?

Chapter 10: Partners and Intimacy

1. Debra describes the tensions and friction that developed due to her wanting to be independent but struggling to do certain tasks. She was at times resentful of Steve helping and not helping her when she needed it. (p. 121)
    - **a.** Has this dynamic occurred in your relationship with your survivor post-stroke?
        - **i.** If so, how was it or could it be remedied?
    - **b.** Do you think it is important to allow the survivor to ask for or confirm a need for help before it is given?
        - **i.** Why or why not?

2. Debra describes how early on, her husband Steve received important advice: “he’d be no good as support for me, if he didn’t take care of himself.” (p. 127)
    - **a.** Do you agree it is important for carepartners to take time for themselves, even in the immediate aftermath of a stroke?
        - **i.** Why or why not?
    - **b.** Were you able to do this and if so, did you find it difficult to do?
    - **c.** In what ways do you take time for self-care now?
    - **d.** What are the obstacles to taking even more time for self-care?
    - **e.** Consider the example of Martina Varnado who occasionally hires someone to help with home responsibilities that she used to take care of. Why does she do this?
        - **i.** If what Martina did is not financially possible, are there people in your support network who could be asked periodically to help alleviate some of your caregiving load?
    - **f.** Do you feel appreciated for your work as a carepartner?

   - **g.** In what ways would you like to be shown appreciation for your work?

3. Debra states, "I have found that sometimes the most helpful support I can provide to Steve is giving him the space and encouragement to do the things that make him happy, without me." (p. 128)
   - **a.** Do you feel able and supported to take time for social, athletic, and other activities alone that you used to do with your survivor?
   - **b.** If that is currently not an option in your life, what types of support would you need in order to build these opportunities into your life?

4. Debra states, "Although sex certainly isn't the only form of intimacy that makes our relationship rewarding, it is an important one." (p. 129)
   - **a.** If your survivor is your romantic partner, what impact has their stroke had on intimacy?
      - **i.** Are there positive and negative impacts?
   - **b.** What forms of intimacy do you and your survivor feel comfortable with since their stroke?
      - **i.** Have these changed over time?
   - **c.** How has your survivor's self-image evolved since their stroke?

5. Debra states, "... so many things in our lives, even sex, are driven not by our capabilities but by our sense of self, our identity, and that our identity is powerfully influenced by those around us, especially those closest to us." (p. 131)
   - **a.** If in a romantic relationship, what impact did your survivor's stroke have on the dynamic between you and your survivor?
   - **b.** What has helped you and your survivor navigate through the different phases of recovery as sexual partners?
   - **c.** How do you strike a balance between providing care and support, and maintaining your role as a romantic partner/significant other?
   - **d.** Has finding this balance been easy to do?

   i. Why or why not?

e. When the balance feels “off”, have you found effective ways to restore it?
   i. If so, how?

Chapter 11: People are Social Animals

1. Sandberg and Grant refer to, “pre-traumatic growth”, or the concept of learning from being close to a trauma rather than actually going through one directly. (p. 137)
    a. Have you gained any insights from your survivor’s journey that have changed you?
        i. If so, how?
    b. Have other people in your life shared any impacts?
    c. If you have not yet taken the time to reflect on the experience, is this something that might be informative or helpful to you?

2. Debra writes that, “Nearly every stroke survivor I talked to had initial difficulties in rebuilding a social life” (p. 138).
    a. Did your survivor find social interaction difficult following their stroke?
        i. Have these feelings changed over time?
        ii. What do you feel might make it difficult for your stroke survivor to rebuild a social life?
    b. Did you find social interaction difficult following your survivor’s stroke?
        i. Have these feelings changed over time?
        ii. Have you been able to rebuild your own social life following your survivor’s stroke?
    c. 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?
    d. What did you and your survivor enjoy or gain from social interactions before their stroke?

    - **i.** Has that changed since their stroke?
  - **e.** In many instances, carepartners are able to find community among other carepartners. Has this been the case for you?
  - **f.** Do you feel interacting with other carepartners is helpful to you?
  - **g.** Are there support groups that you enjoy attending virtually or in person?
    - **i.** If so, share some of them with your group.

3. Debra writes "When I'm feeling particularly down, I try to recognize that need to give myself a little time to feel down and angry about my stroke … When time is up, I can appreciate having given myself space to acknowledge the bad stuff, and it usually helps me refocus on looking forward." (p. 143-144)
  - **a.** Do you feel your survivor generally has a positive attitude?
    - **i.** If so, how has it helped in recovery?
  - **b.** Do you generally have a positive attitude?
    - **i.** If so, how has it helped during your survivor's recovery?
  - **c.** When feeling less positive, do you or your survivor allow space for self-compassion about the difficulties you're facing?
    - **i.** Is it difficult to shift back into gratitude and a positive mindset?
  - **d.** What tools or techniques do you use to work through these feelings?

4. Consider the example of Randy and Rose who started their own aphasia Meetup group. The group has provided them with new friends, and Randy shared that he, "enjoys practicing speech in this safe zone." (p.143)
  - **a.** Why do you think this group has been so helpful to Randy and Rose?
  - **b.** Would you consider starting your own group for your survivor or other carepartners?
    - **i.** If so, describe your goals for creating a new group.

- **c.** What are some ways to bring other carepartners together and get them to engage?
    - **i.** Since it may be difficult to meet in person, would you consider utilizing video meeting platforms such as Zoom or Skype?

Chapter 12: How the World Responds

1. “The world is not oriented toward accommodating those with disabilities, and there is little we can do to avoid a fairly constant barrage of insensitive actions.” But Debra also states, “We can armor ourselves: create a separation between our internal feeling of self-worth and the external world’s treatment of us.” (p. 150).
    - **a.** Has your survivor used armoring to maintain their sense of self-worth? Have you?
    - **b.** What other strategies have you and your survivor found to be helpful?
    - **c.** How easy or hard is it for your survivor to de-personalize interactions with others?
    - **d.** How do you as the carepartner help navigate these circumstances with your survivor?
    - **e.** Have you had situations with your survivor or others in your role as carepartner where you found it helpful to use armoring and de-personalize interactions?
    - **f.** Have you or your survivor found ways to educate others about stroke impacts and related sensitivities and needs?

2. Debra states that, “feeling sorry is about the situation, and feeling pity is about the person.” (p. 154)
    - **a.** How have people reacted to your survivor since their stroke?
    - **b.** How have people responded to you as you navigate your life as a carepartner?
    - **c.** What do you wish people understood about what it feels like to be a carepartner?

Chapter 13: Activities Adapted

1. Debra writes that “the activities that we fill our time with are one of the purest expressions of what we care about and how we define ourselves.” (p. 157)
    - a. What are some activities that you most enjoyed pre-stroke that are challenging to do now?
    - b. What is it about these activities that you value?
    - c. Have you explored other potential ways to fulfill these values?
        - i. Why or why not?
    - d. What are some activities that your survivor most enjoyed pre-stroke that are challenging to do now?
    - e. Have you explored with your survivor other potential ways to fulfill these values?
        - i. Why or why not?
    - f. How have activities you did together changed post-stroke? Are there new or adapted activities that might provide you with a similar sense of fulfillment? For example, if you used to bike together, is a tandem bike an option?

Chapter 14: Careers and Callings

1. Debra writes about how important work and her career were to her identity. (p. 164). If work is still a part of your and your survivor's lives,
   a. How has your survivor's stroke and your carepartner role impacted your ability to work?
   b. How do you feel about any career changes you have chosen or been forced to make?
   c. How has your identity been impacted due to these work changes?
   d. How has your survivor's stroke impacted their ability to work?
   e. If your survivor was unable to return to work, how challenging has it been to incorporate this change into their identity?
   f. If in a committed relationship, how have your and/or your survivor's work changes impacted your life together?
      i. Are you able to identify both benefits and costs?

2. Debra writes that she, "felt that teaching was akin to a calling, and that is perhaps the loss I continue to struggle with most." (p. 172)
   a. How would you describe your professional identity before your survivor's stroke?
      i. Has that identity or its importance to you changed?
   b. What other ways can you honor or express the values fulfilled by your career in your life? For example, if you needed to reduce your commitment to a career you enjoyed, are there other ways that you can create a similar sense of purpose?

Chapter 15: Dealing with Financial Strain

1. Debra writes, “Almost every stroke survivor I’ve met has stories about how life is changing because of financial pressure, from minor to dramatic.” (p. 178)
   a. What impact did your survivor’s stroke have on your family’s financial 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. Have you explored public or private forms of financial assistance or considered avenues like clinical trials that may help?
   e. If you’re still experiencing financial hardship, are there additional steps you can take to find resources and support?
   f. Has your survivor inquired about the specifics of any financial burdens on you?
   g. Have you discussed any hardships with your survivor?
      i. If so, were you candid in your response?

2. Debra shares that stroke survivor Randy’s wife felt, “their plans [for the future] were stolen.” (p. 181)
   a. Do her sentiments resonate with you?
      i. If so, how do you feel your future has changed?
   b. How difficult has it been to come to terms with this new reality for the future?

Chapter 16: Advocating in the U.S. Medical System

1. Debra writes that as her “condition improved, I had to be my own advocate.” (p. 183)
   - **a.** Were there any examples of stroke survivors and their families advocating for themselves that you found inspiring in the book?
     - **i.** Which ones and why?
   - **b.** What was your experience navigating the medical system in the aftermath of your survivor’s stroke?
     - **i.** Did it change as you became more experienced advocating for your survivor, or as you moved from the acute medical environment to rehab and other care settings?
   - **c.** Have you had success in advocating for your survivor as well as for your own needs?
     - **i.** If so, share some examples that make you proud.
   - **d.** What have been your biggest barriers or hurdles as an advocate?
   - **e.** What advice would you give to survivors and carepartners who are still early in recovery?

2. Consider Jim Indelicato. After his stroke, his wife Diane recounted how “it often felt…as if nobody was looking past his immediate survival.” (p. 185)
   - **a.** Why does Diane’s daughter suggest bringing a photo of “how Daddy was” into the hospital?
     - **i.** What is the impact of sharing this photo with the hospital staff?
   - **b.** Do you utilize any meaningful objects or symbols from pre-stroke life?
     - **i.** What impact do these items have on you and how do they make you feel?
   - **c.** Does your survivor utilize any meaningful objects or symbols of their

pre-stroke life and identity?
   - **i.** What impact have these items had on their recovery?
- **d.** Do these items have an impact on you and how you care for your survivor?
   - **i.** Has the impact changed over time?
- **e.** Does your survivor avoid any objects or symbols of their pre-stroke life and identity?
   - **i.** Does this have an impact on you and how you care for your survivor?

Chapter 17: Reclaiming the Basics

1. Debra writes, "Recovery isn't about getting back to exactly who we were. Instead, the goal is to reclaim the pieces that mean the most to us." (p. 195)
   1. Has your survivor been able to reclaim meaningful pieces of their life as well as find new, meaningful pieces?
   2. Have you been able to reclaim meaningful pieces of your life as well as find new, meaningful pieces since becoming a carepartner?
   3. Has it been difficult to balance the needs and desires you have with those of your survivor?
      - **i.** Why or why not?
      - **ii.** Has this balance shifted over time, or might it in the future?

2. For many survivors, early recovery must focus on addressing basic skills and needs. Debra states, "The lack of clarity about the future is stressful. It becomes hard to balance acceptance of the situation with determination to push rehab hard, both of which are important." (p. 196)
   - **a.** How challenging has it been for you to find a balance between a determination to push for improvements and acceptance?
   - **b.** How challenging has it been for your survivor to find a balance between a determination to push for improvements and acceptance?
   - **c.** If you and your survivor are not in the same place regarding acceptance, how does this difference impact you and your relationship?
   - **d.** What makes it difficult to find balance?
   - **e.** What helps you and/or your survivor to find balance and acceptance?

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

Chapter 18: Choice in Our New Identities

1. In describing life post-stroke, Debra mentions the Japanese art of kintsugi, where "broken pottery is repaired with gold or silver, mending the cracks." (p. 206)
    - **a.** Is this a good metaphor for how Debra and many of the other survivors have approached their post-stroke life?
        - **i.** Why or why not?
    - **b.** Would you use kintsugi or a different metaphor to describe your own life post-stroke?
        - **i.** Your survivor's post-stroke life?
    - **c.** Consider Julia Fox Garrison's decision to celebrate her "stroke anniversary." Does this approach resonate with you?
        - **i.** Why or why not?
    - **d.** How do you and your survivor approach the anniversary of their stroke?

2. Debra writes about the importance of goal setting to her recovery and her emotional well-being. (p.212)
    - **a.** To date, has your survivor been able to set and accomplish goals on the recovery path that they find meaningful?
        - **i.** What are some additional goals you would like to see your survivor address in the future?
    - **b.** To date, have you been able to set and accomplish personal goals in concert with your survivor's recovery?
        - **i.** What are some additional goals you would like to address in the future?

c. Have you found it challenging to set goals that are specific and realizable, especially in the context of an often uncertain stroke recovery horizon?

i. Why or why not?

Chapter 19: Fulfillment Through Growth

1. Consider the structure of *Identity Theft*. The book begins and ends with Debra introducing herself. At its conclusion she writes “I am still me, stubborn and determined. *I am Debra Meyerson.*” (p. 223)
    a. Do you think that Debra is still the same person?
        i. In what ways has her identity evolved?
    b. In *Identity Theft*, stroke is discussed as a family illness—that everyone’s identity may be impacted and changed. Would you describe yourself differently since your survivor’s stroke?
        i. If so, how have you changed?

2. Debra chose to name the book “*Identity Theft*” very deliberately.
    a. Do you think this was an appropriate title choice?
        i. Why or why not?
    b. Do you feel robbed of any aspect(s) of your identity?
        i. If so, how?
        ii. Have any aspects of identity been gained?
    c. How has your survivor’s identity changed post stroke?
        i. Do you feel any parts of your survivor’s identity have been lost?
        ii. Have any been gained?
    d. Think of the other survivors profiled in the book who were most successful in creating a new identity for themselves. What factors helped them?
    e. Based on what you read, are there additional things that you might do to encourage your survivor’s progress?
    f. Based on what you read, are there additional things that you might do to enhance your life as a carepartner?

g. How do you hope your survivor will describe themselves in the future?

h. How do you hope to describe yourself in the future?

Appendix 1

1. Debra writes that the people she interviewed for *Identity Theft* are “all incredible people who are on heroic journeys,” and says that, like her, you “may see bits and pieces of yourself or your loved ones in many of them.” (p. 236)
    - **a.** What impact did including stories from other survivors, their families, and the practitioners who helped them have on you?
    - **b.** Did reading about recovery from different perspectives change your own perspective on anything?
        - **i.** If so, what?
    - **c.** Will reading about these different perspectives impact the way you provide care?
    - **d.** Think of other carepartners profiled in the book. Who do you relate to most and why?