

Identity Theft: Rediscovering Ourselves After Stroke

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Chapter 4 Summary: Moving Forward

Four years after her stroke, Debra speaks to health care workers, stroke survivors, and advocates at a Pacific Stroke Association event. Debra practices and practices her 10-minute speech she calls “Lucky to Be Alive.” She surprises herself when she comes out with a sentence she hadn’t planned to say, “I am a happier person now.” Other times, she has also found herself spontaneously saying “Life sucks,” especially when she is mourning the loss of her old self. Debra acknowledges you can feel both ways. She describes research about coping with chronic illness. Some researchers developed a framework for a process they call, “Narrative reconstruction.” It describes three common states of mind in chronic illness: **1. Chaos Narrative**, loss of hope; **2. Restitution Narrative**, focus on recovery; **3. Quest Narrative**, opportunity for growth. Debra explains that she switches between these states of mind. One day she feels completely optimistic about recovery. Then the next day, she may feel completely hopeless. Debra reflects on **the role of resilience**. She says that it is not just something we have or don’t have. Rather, we can build and reinforce our resilience. She still has low moments, but she can recognize which narrative she is in and tries to adjust. Debra admits she may never stop being frustrated by her lost abilities, but she is moving forward.

Debra offers **three major strategies** that have helped her to rebuild her life and identity. She’s heard these themes in the stories of other stroke survivors. **1. Look forward, not back: *Focusing on small wins*** in the future instead of making comparisons to her past life is key to continued progress. Stroke survivor and activist, **Julia Fox Garrison**, promotes being a survivor and not a stroke victim. Julia believes that a good attitude, leads to a better outcome. Debra says focusing on small wins is *hard* and she believes that we have to accept the times we feel frustrated and need to grieve. She says the aphasia is a constant reminder of what she’s lost—she can think of the ideas in her head but can’t express those thoughts to others. Debra explains a strategy called

“leaning into the suck.” You think about how bad it is, but then you think about how it could worse. It reminds Debra to think of her blessings, then she can refocus on what she values in life and set doable goals for the future. She says we are wired to adapt, and that happiness can follow. **2. Focus on deeper values:** Debra explains that understanding what one cares about the most, be it family, fitness, advocacy, or faith, can be both a source of motivation and a guide to setting goals. Stroke survivor Julia Fox Garrison says she often asks herself, “How do you change something that you love and make something else new, introduce new things into your life that can bring you joy?” It is a process of “sensemaking” and finding meaning to a new way of being. **3. Seek opportunities for growth:** Debra sees that stroke, like all trauma and setbacks, can offer opportunities for valuable growth. Focusing on silver linings and “bouncing forward” are key concepts.

Chapter 4 Highlights: Moving Forward

1. Four years after her stroke, Debra’s “choppy speech” starts to come back. She is invited to speak at a Pacific Stroke Association event. It is her first public speech with aphasia. She practices over and over. Debra gives a 10-minute speech called, “Lucky to Be Alive.” She surprises herself by adding a new sentence: “I am a happier person now.”
2. Other times, she has found herself spontaneously saying, “Life sucks.” There are times when she mourns the loss of her old abilities. She admits that both feelings are true. Some days she feels like life sucks. Other days, she feels she is genuinely happier now.
3. Debra describes the work of researcher Dr. Kuluski and colleagues who study “narrative reconstruction” in chronic illness. They proposed three common states of mind in chronic illness: **1. Chaos Narrative**, loss of hope; **2. Restitution Narrative**, focus on recovery; **3. Quest Narrative**, opportunity for growth.
4. Debra admits to switching among all three states of mind. Sometimes she is focused on the loss and feels hopeless. Sometimes she is completely focused on her physical or speech recovery. Some days she is grateful for her new insights about life and her work to help other stroke survivors. She thinks understanding this framework helps her to “dig out” of the Chaos Narrative faster and to keep her in quest frame of mind more often.
5. Debra points to the power of resilience in facing adversity. She says resilience isn’t just an innate ability. It can be built and reinforced. She still has low moments, but she can recognize which narrative she is in and tries to adjust. It has helped her to build resilience.
6. Debra has found three strategies that has helped her in the process of rebuilding her life and a positive identity. She has found that many stroke

survivors she has interviewed share these strategies. They are: **1) Look Forward not Back, 2) Focus on Deeper Values, and 3) Seek Opportunities for Growth.**

7. Looking Forward, Not Back: Julia Fox Garrison is a stroke survivor and activist. Julia tells Debra that she may never fully recover all of her abilities, but she will never give up trying. She prefers the term “survivor” with the focus on thriving versus stroke victim. Julia thinks working on continuous improvement instead dwelling on loss and a good attitude lead to a better quality of life. Debra admits that she sometimes feels fed up with her weak hand, her limp, or her difficult speech. But folks remind her to look at the progress she has made over time and it helps her to recognize the improvements.

8. Debra describes how the concept of “*small wins*” can have a huge impact on how we think of our situation. She explains how it helps people in frustrating situations by breaking down big goals into smaller, more manageable bits that feel more doable.

9. Debra admits that focusing on small wins is hard. It’s also important to give yourself permission to feel frustrated, imperfect and even to grieve. With aphasia, it’s particularly hard when you can form the thoughts in your head, but you can’t get them out to others. This disconnect can be a constant reminder of the loss.

10. During these moments, Debra relies on the concept “*leaning into the suck*” by thinking about all the things that are hard, but then thinking about how it could be worse. This helps to restore your focus on your blessings and to set doable goals for the future. Debra reminds us that humans are “wired to adapt, and our happiness can follow.”

11. Debra interviewed **Mark Wells** who wondered after his stroke if he'd be better off dead. He started to find inspiration in several places, including his faith. He decided he had to learn how to be content. He knows some people are worse off and that others are doing well. He decided he wanted to be doing well too.

12. **Focus on Deeper Values:** Debra explains that understanding what you care about the most, be it family, fitness, advocacy, religion, or some other cause, is a source of motivation and for guiding your actions. Julia Fox Garrison realized that recovery wasn't just returning to "pre-stroke Julia", but rather rebuilding a life of meaning and joy.

13. Debra introduces the idea of "**sensemaking**" offered by social scientist, Karl Weick who also developed the idea of "**small wins.**" It's important in the recovery life's setbacks to find meaning in your experience. Understanding your strengths and resourcefulness in facing adversity can build resilience. It's a challenging process, but it can promote personal growth. Debra shares the stories of several stroke survivors who each worked hard to find new meaning in their lives through faith, personal awareness, or advocacy.

14. **Seek Opportunities for Growth:** Debra suggests that asking "what can I take away from this?" is critical to promoting personal growth and recovering with strength and resilience. She explains the concept of "**bounce forward**" where people grow past where they were before their stroke. Debra describes stroke survivors who now laugh more, feel more appreciative and more positive. Debra admits for a long time she could only see what "sucked" about her stroke. Overtime, she has found silver linings. It's a hard process, but she is convinced that "I can rebuild a full life, even if I can't recover all of my past capabilities." She now thinks of recovery as being at the top of Maslow's pyramid—focusing on the quest for meaning and growth.

Chapter 4 Points for Reflection: Moving Forward

1. Debra surprised herself by saying “I am a happier person now.” Did it surprise **you** to read that Debra was **happier now** than before her stroke?

Not at All			Somewhat Surprised				Very Surprised		
1	2	3	4	5	6	7	8	9	10

2. Debra says that less work stress, laughing more, having more time for and a deeper appreciation of family and friends, enjoying food, finding a new meaningful role as a stroke educator are some of her positives. Have **you** found **positives** from your **stroke journey**?

Not at All			Some Positives				Important Positives		
1	2	3	4	5	6	7	8	9	10

3. Julia Fox Garrison feels a **positive attitude** has a huge impact on outcomes. Do you think that **attitude** plays a **large role** in **your recovery and adjustment**?

Not at All			Somewhat				Absolutely		
1	2	3	4	5	6	7	8	9	10

4. It took Debra a long time before she could acknowledge anything good could come out of her stroke. She shared a strategy, “**leaning into the suck.**” Does the idea of admitting what’s hard, but then thinking about how it could be worse and **focusing on your blessings** seem **helpful to you**?

Not at All			Somewhat				Absolutely		
1	2	3	4	5	6	7	8	9	10

5. Debra has found that focusing on “**small wins**” helps to make working on recovery feel more doable and helps her to set realistic goals for ongoing improvements. Has **setting recovery goals for yourself** been an **easy or difficult challenge**?

Very Difficult				Moderate Challenge					Easy to Do
1	2	3	4	5	6	7	8	9	10

6. Debra talks about switching between feeling optimistic one day and mourning her losses another day. **What helps you** to move from “**chaos**” (**loss**) to a **focus on “quest”** (**growth**)?

7. Many stroke survivors in this chapter talked about developing new interests or insights about themselves. What **new activities or insights** have you **gained** since **your stroke**?

8. What is your most important “take away” from this chapter?