

## 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 do not 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 has 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 has 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 be 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 **Chaos Narrative** faster and to **keep her in a quest frame** of mind **more often**.
5. Debra points to the **power of resilience** in facing **adversity**. She says **resilience** is not 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 found **three strategies** that have **helped** her rebuild her life and a positive identity. Many stroke survivors she interviewed share these strategies. They are:

- 1) Look Forward not Back;**
- 2) Focus on Deeper Values;**
- 3) Seek Opportunities for Growth.**

7. **Look 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 of dwelling on loss and a **good attitude** lead to a **better quality of life**. Debra admits that she sometimes feels fed up. 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 to break down big goals into smaller ones. More manageable steps feel more doable.**

9. Debra admits that **focusing on small wins is hard**. It is also important to **give yourself permission to feel frustrated, imperfect** and even to **grieve**. With aphasia, it is particularly hard when you can form the thoughts in your head, but you cannot express them 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 is 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 is a challenging process, but it can promote personal growth.
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. Some stroke survivors 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

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 shares positives in her life after stroke like less work stress, a deeper appreciation of family and friends, and more laughter. 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. Debra shared a strategy, “**leaning into the suck.**” The idea is to **admit when something is hard** but then **think about how it could be worse** to help **focus on your blessings**. Does this strategy seem **helpful to you?**

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

5. How would you **describe your attitude today? Has it shifted over time?**
  
6. Debra has found that focusing on “**small wins**” helps to make recovery feel more doable. Can you share an example of a small win goal that you have met?
  
7. Debra talks about switching between feeling optimistic one day and mourning her losses another day. Is it **important to give yourself permission to feel both ways?**
  
8. **What helps you to move from “Chaos” (loss) perspective to a focus on “Quest” (growth)?**
  
9. Many stroke survivors in this chapter talked about developing new interests or insights about themselves. Since your stroke, what **new activities** have you **started?** Have you **gained new perspective** about yourself?
  
10. What is your **most important takeaway** from this chapter?