Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 1 Summary: A Slow Fall Off a Cliff

On Labor Day weekend of 2010, Debra and her husband Steve headed to Tahoe with two of their kids and their dog. They looked forward to a relaxing weekend before she started teaching fall classes at Stanford. But something felt wrong with her leg and she had a bit of a headache. When they took a favorite hike, it was too hard to walk so they had to turn back. They returned to the cabin so she could rest. By the next morning, her headache was worse. Both her right hand and leg were feeling weak. Steve knew something was wrong and insisted they head to the hospital. A CT scan showed she had a stroke. Debra was quickly sent to a larger hospital in Reno. Her family was scared. Overnight, her symptoms slowly progressed. They called it "her slow motion fall off a cliff." They didn't know what was causing the stroke. They would learn later that she had a small tear in her carotid artery. Watching her condition deteriorate by the hour, Steve felt helpless. By morning, she could not move the right side of her body or say any words—or even make a sound.

As soon as she was stable, she was flown to Stanford Hospital and admitted directly to the ICU. Her mom flew up from Los Angeles to be with them. Her middle son, Adam, flew home from college in Boston. They put a feeding tube in her nose since she couldn't swallow. Debra was now one of the 800,000 people a year who have a stroke—and just 25% of those are 65 or younger. Debra tells the way five different stroke survivors experienced the first symptoms of their stroke. She remembers how she felt in those early days—helpless, scared, confused, broken. She lost her temper when she heard doctors talking in the hall with Steve. She wanted to be included. Debra wanted to know about the "outside world" to help her feel more connected. During a visit with her brother in the ICU, he told her a funny family story. Suddenly, she made a noise like a laugh. Her first sound. That was a good sign. But at night, when she was alone, she wondered how she could live a life without speech.

Chapter 1 Highlights: A Slow Fall Off a Cliff

1. On Labor Day weekend, 2010, Debra and her husband, Steve, headed to Lake Tahoe for a relaxing weekend. She'd soon have to start teaching Fall classes at Stanford again. They had their young adult son, Danny, teen daughter, Sarah, and dog, Kaya, with them. Their middle son, Adam, was just starting college in Boston at Tufts.

2. Debra's right leg was feeling weird. When they got to Tahoe, she thought a good walk would help. She was surprised that her leg felt weak and she couldn't step normally. They had to go back to the cabin. She had a mild headache too.

3. The next morning, her headache was worse. Steve noticed it was hard for her to use her right arm to pick up the aspirin. He put the signs together: Right arm, right leg, headache. She didn't notice anything strange, so she argued when Steve said it was time to head to the hospital.

4. They started off at Tahoe Forest Hospital, but the CT scan showed she'd had a stroke. They transferred her to Renown Hospital in Reno by ambulance. Her family tried not to panic. What did this all mean?

5. They did more tests at the Reno hospital. Her speech was starting to slur. The doctors couldn't tell them much about why this happened or what to expect. Adam caught a flight home from college right away. He knew a stroke was serious.

6. Sarah didn't know how bad strokes could be. This was all new to her. Debra can't remember much from those early days, but her family tells her she was frustrated. They remember being scared.

7. Debra explains that recognizing the signs of a stroke is critical. She explains: **FAST**. **F**ace = look for an uneven smile, **A**rm = one weak arm, **S**peech = slurred speech, **T**ime = Call 911 right away. There is a drug, tPA, that can help break up a clot, but you must take it within 4 hours of your stroke. There are new surgical ways to break up a clot too.

8. Later on, they would learn that she had a small tear in her carotid artery shut off the blood flow to her brain. This was not a common cause of a stroke. There was no warning.

9. Between Sunday evening and Monday morning, Debra's symptoms got worse by the hour. Steve felt helpless. They describe that night as her "**Slow motion fall off a cliff.**" By the morning, her arm and leg were paralyzed. She couldn't say a word or even cough. She couldn't respond, but Steve felt she was "still there."

10. Debra was stable enough to be flown to Stanford. They wanted to be close to their home. Her mom flew up from Los Angeles to meet them at the hospital.

11. Debra had complications that kept her in the ICU. There were no clear answers as to why she had the carotid dissection (tear of the artery). Her stroke was not typical--but each stroke is unique. She needed a feeding tube in her nose for nutrition.

12. Her family felt frustrated and scared. They were not used to seeing their strong, active mom unable to talk or move. Debra's mom remembers it was devastating, terrifying, depressing, and horrible. She did not like seeing her daughter helpless.

13. She was one of 800,000 people who have a stroke in the U.S. each year. A quarter of the strokes happen in people 65 or younger. Many have no traditional factors or history. Many strokes are misdiagnosed at first as a headache or dehydration.

14. Debra introduces 4 stroke survivors and shares their stroke stories:

1. **Isaiah Custodio**: He was at football practice when he experienced a very bad headache, then vomited and fainted. Isaiah was only 13 years old.
2. **Kathy Howard**: Her stroke happened on her 31st wedding anniversary. She saw a black hole on the TV screen, threw up, saw red and green.
3. **Sean Maloney**: He was to be Intel's next CEO. His stroke was sudden, but he describes it as peaceful. He thought "That's it, I'm gone."
4. **Cindy Lopez**: She thought she was fine and thought her husband was making a fuss. It took her two days to realize that she couldn't move parts of her body.

15. Debra recalls how the uncertainty and lack of control was unbearable. She felt helpless, confused, and broken. If she heard doctors talking with her husband without her, she lost her temper. She wanted to be included.

16. While in the ICU, she liked hearing about stories "of the outside world." It made her feel more connected. Her brother told her a funny story. She made her first sound, like a laugh. That was a good sign. They tried hard to come up with other stories to make her laugh. But alone at night, she wondered what life without speech would be like.

Chapter 1 Points for Reflection: A Slow Fall Off a Cliff

1. Debra's first sign was that her leg felt "funny", but she didn't realize it could be a sign of a stroke. What were the first **signs of your stroke**? (Circle all that apply.)

Lost Consciousness Speech Problems Swallowing Problems

Numb Face Headache

Weak Leg or Arm Vision Problems Other

2. Debra can't remember the early days of her stroke. How well **do you remember** those first days after your stroke?

No Memory Remember Some Remember Everything
1 2 3 4 5 6 7 8 9 10

3. Why did they call this chapter "**Slow Fall Off a Cliff**"?

Her symptoms slowly got worse. She fell off the cliff when hiking. I don't know.

4. Debra felt the **uncertainty** about her recovery was very **stressful**. Were **you worried** about your **recovery** in those early days?

Very Worried Somewhat Worried No Worries at All
1 2 3 4 5 6 7 8 9 10

5. It took a while for Debra's medical team to figure out what caused her stroke. How **easy or hard** was it for your doctors to figure out **what caused your stroke**? What were you told was the cause of your stroke?

6. At first, Debra was completely mute–she couldn't even nod her head yes or no. What was **your speech** like right after your stroke? What do you remember about your **first sound or words**?

7. Why did Debra **lose her temper** when she heard the doctors talking to her husband in the hall? What was **most frustrating for you** in the hospital?

8. Debra was scared that the lack of speech would cut her off from the people she loved. What were **your first feelings** or thoughts about your **challenges with communication** after your stroke?

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Chapter 2 Summary: Everything Can Fail

Debra starts her acute inpatient rehab at a new hospital. Steve heads back to work and returns to a more regular routine. Debra still has no speech. She is terrified because she still can't talk. Her speech therapist helps her hum and then sing simple songs. She finally produces her first words! He uses melody and rhythm to help her say, "My name is Debra Meyerson." She repeats it over and over. This breakthrough comes with tears of joy. Debra explains to the reader that "there is no cure for stroke." Each stroke is different. It is hard for patients to know what their recovery will be. There are fears about loss of control of the body and of having another stroke. She writes about **Sean Maloney**, a former Intel exec whose stroke left him with aphasia and a paralyzed right side. He describes it as a shattering loss of wholeness. He realized that "everything can fail."

Debra makes good progress with her walking and talking for two weeks. But one morning it's harder to talk again. A CT shows another stroke in her speech centers and she's transferred back to Stanford. Medical complications lead to more time in the ICU. She is furious at this set back. She is still planning to be back at work in two weeks. The doctors discover the second stroke was caused by a clot that formed behind the tear in her carotid artery. The family agrees to a risky surgery to put in a stent. They worry when the surgery takes much longer than expected but are relieved when it's a success. Debra is soon back at the acute rehab hospital working on her recovery. One morning, her son, Danny, arrives to find his mom face down on the floor. Debra couldn't move or call for help. She won't admit to the nurses or Danny that she decided to try walking on her own. She was sure her willpower would be enough to make her body work. All her life, she has overcome challenges and met her goals. Debra shares that early after her stroke, she was still holding on to her old identity. Stroke changes your capabilities in an instant. Some survivors, like Debra, stay in denial for a long time. Others adjust more quickly to the losses. Her sense of self was now threatened. Debra says, she "was a teacher without words."

Chapter 2 Highlights: Everything Can Fail

1. Debra starts rehab at her 4th hospital, Santa Clara Valley Medical Center. Steve returns to work which helps him feel a sense of routine and normalcy again.

2. Her son, Danny, is there for her first session with her new speech therapist, Jonathan. He can tell she is terrified and desperately wants to talk. She can barely make a sound.

3. Jonathan starts by asking Debra to hum along to the tune Happy Birthday. He moves her arms to the rhythm. She starts to hum and finally she gets out her first word, "You." She was overjoyed. He quickly gets her to practice other simple tunes. She gets more words.

4. Next, he makes up a tune for her to chant the phrase, "My name is Debra Myerson." After a few tries, she can say/sing the phrase. She practices saying it over and over. The melody and rhythm are a powerful way to unlock her fluency.

5. Later, Danny shares an update in their Caring Bridge blog about his mom's joy at her first words. He tells how, with tears streaming down her face, she kept practicing.

6. Debra quotes a medical researcher who says "There is no cure" for stroke. Through brain scans and medical history, we know that every stroke is different.

7. The nature of how strokes happen can damage a person's sense of self. It often strikes without warning. The cause is often unknown or random. We don't know how much or how fast survivors will recover. Losing control over your body can feel frightening and like a failure.

8. Debra tells how Intel Executive, **Sean Maloney's** stroke left him unable to speak or use his right side. Many years later, he still remembers the "shattering loss of wholeness and control" after his stroke. It was hard to realize that "everything can fail."

9. Stroke survivor **Andrea Helft** told Debra that she was afraid of having another stroke. It could be life threatening. It's hard to live with uncertainty and lack of control.

10. Debra made good progress for two weeks. She could walk down the hall. She could say more and more words. But one morning, her speech came out garbled again. She tried desperately to prove everything was okay, but she couldn't get the words out.

11. Steve quickly got a hold of the doctor. A new CT scan confirmed a second stroke. They felt devastated. Debra was sent back to Stanford.

12. They discovered the tear in the carotid artery caused another clot. Low blood pressure and low platelets kept her in the ICU.

13. She kept her physical strength she had regained, but the new stroke was in her speech center. She lost her speech again.

14. Debra was furious about the set back. She wanted therapy in the ICU, but it was limited. Her family tried to help her with PT and Speech exercises. Her husband compared stroke recovery to a series of steps forward and then a few backwards.

15. Debra couldn't make a sound, but she wanted to work on speech. She was determined to be back at work in two weeks. She still saw herself as Professor Meyerson.

16. The doctors recommended that the family consider brain surgery to put in a small stent to prevent another blood clot. It was a risky procedure and a hard decision. The doctors thought not doing the surgery was risky too. The family decided to do the surgery.

17. The family waited while she was in surgery. It was supposed to take 2-3 hours, but it took over 5 hours. The family worried something went wrong. Finally, they learned surgery was a success. Soon, she headed back to Valley Medical Center for more rehab.

18. Danny went to visit his mom but was shocked to find her face down on the floor. Debra had fallen and couldn't move by herself or call for help. He tried to help her up, but she pushed him away. Debra kept saying the only word she could, 'No, no, no, no."

19. Debra wouldn't admit it to Danny or the nurses, but she had decided to get up on her own and walk. She was sure if she tried hard enough, she could do it. While her determination and stubbornness were an asset, her denial could have resulted in a terrible injury.

20. Debra didn't understand yet that her condition would be long lasting. She assumed it would just take effort to get everything back. She'd always worked hard and met her goals, figuring out any problem that stood in her way. One year, she and Steve even sailed around the world in a sailboat with their kids. They made it happen despite obstacles.

21. Debra tells the tale of the father of one of Danny's good friends who was also a professor. He'd also had a carotid dissection followed by aphasia and right sided weakness. He too tried to get out of his wheelchair on his own and had fallen. His son discovered him on the floor. Like Debra, he would not admit that he decided to get up on his own. He wasn't ready to accept his new reality. They shared the same story.

22. Debra discusses that many people like her have a hard time early on after the stroke accepting changes in their capabilities. They cling to what they could do pre-stroke.

23. Debra admits it's a hard adjustment. Determination keeps you working on your recovery. But denial of the changes in your abilities can **keep you stuck** on your old identity **instead rebuilding** a new one.

24. Some people seem to adjust quickly. Many others stay in denial for a long time before struggling with who they were and who they are now. Debra realized she was now a teacher without words.

Chapter 2 Points for Reflection: Everything Can Fail

1. Debra remembers her **first words** after the stroke. How well do you remember your first words?

Not at All | Some Memory | Strong Memory

2. Debra speaks about the **feelings of uncertainty** after a stroke because no one can tell you for sure how much you will recover or how fast. How uncertain did you feel at first?

Not at All | Some Feelings of Uncertainty | Strong Feelings

3. Debra's husband, Steve, says that you can take **steps forward and backwards** during stroke recovery. Did you feel like there were many ups and downs during your recovery?

Not at All | A Few | Too Many!

4. Debra talks about the challenge **balancing determination** and **realistic expectations**, especially early after the stroke. Did you find this a difficult balance?

No Problems | Some Problems Balancing | Very Hard to Balance

5. Debra said Steve's return to work helped him regain an **everyday routine**. How important was it to you and your family to get back to a sense of normalcy?

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

6. Why do you think **Debra denied** that she tried to get up and walk away from her wheelchair? Did you ever do something after your stroke that you realize now wasn't a safe idea?

7. Debra still couldn't talk, but she wanted to be back at work in two weeks. Describe what **your adjustment process** was like. How quickly did you realize your changes in abilities?

8. What part of this chapter **resonated the most** with you as you think back on the time right after your stroke?

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Chapter 3 Summary: A Teacher Without Words

Before her stroke, Debra was a professor at Stanford University. In 2001, she published a book called, *Tempered Radicals*. It was about people with identities that do not fit easily into big organizations. Debra studied the concept of "identity" for many years. She loved her work.

People have many different identities. Identities also change over time. For example, Debra was a student and daughter when she was young. Then she became a professor, wife, and mother. Our identities are shaped by the things and people that are most important to us. When Debra had a stroke, she felt she lost her old identity. Suddenly, she was an athlete who needed help to walk. She was a teacher who was unable to speak. She tells a story about **Manny Gigante**, another survivor who worried he could not protect his family.

After Debra's stroke, she worked very long and hard to recover. She was determined to get her old life back. But three years later, her speech was still difficult. She had to give up her job at Stanford. She was very hurt and scared about her future. Slowly, Debra began to think differently. She thought about the things in life she valued most and why. She knew she still could make choices about her life. She asked herself a very important question: who do **I want** to be **now**?

Debra remembered a tool she had studied developed by a famous psychologist named Abraham Maslow. It was a pyramid that described the different needs that must be met for people to feel happy and fulfilled. Basic needs like food and safety were at the bottom. In the middle were psychological needs like strong relationships with friends and family. Only at the very top did people feel fulfilled. Debra had been there. Debra started at the bottom of the pyramid after her stroke. Her desire to be independent motivated her a lot. She decided to find a new way to teach. She could still inspire people. She could still share knowledge. She could find meaning and purpose in her life again. With help, she could write another book.

Chapter 3 Highlights: A Teacher Without Words

1. Debra tells us about her life before her stroke. She was a university professor and consultant. She was passionate about her work. In 2001 she published a book called *Tempered Radicals*. It was about people whose personal identities sometimes made it hard for them to fit easily into big organizations. Debra studied the concept of identity as a scholar for many years.

2. People often define their identity by their roles in life. We each have multiple identities that change with time. For example, Debra was a student and daughter. Then she became a professor, wife, and mother. Our identities relate to other people. They also reflect the things that are most important to us.

3. When Debra's stroke happened, she felt that the old ways she defined herself were no longer true. She was confused about her identity. She was an athlete who now needed help to walk. A mother who was comforted by her children.

4. Debra introduces **Manny Gigante**, another stroke survivor. Manny was a hard working software engineer in California. When he was 29 years old, he had a bad stroke. Manny's young son died in an accident after Manny's stroke. Could Manny have stopped the accident before his stroke? Using a wheelchair made him worry he could not protect his family.

5. After Debra's stroke, her life changed a lot. This was very difficult for her to accept. She was stubborn and refused to give up her career at Stanford University. It was something she had worked so hard to build. She wanted to ski and bike. She wanted to go on adventures with her family. She kept working hard to recover her old life.

6. Three years after her stroke, Debra's speech was still difficult. She could not teach and research at Stanford anymore. She was very hurt. And she was very scared about her future. She cared a lot about her work and the topics she studied. Who would she be without them?

7. Debra tried to accept that her life had changed. It was very hard. She was so frustrated. Sometimes she felt hopeless and trapped. Her emotions were complex and scared her. Debra started to wonder if she had lost important parts of her life and identity forever.

8. Slowly, some of the ideas Debra had once taught as a professor began to help her. She tried to understand what made her happy and why. Debra realized she still could make choices in her life. She asked herself a very important question: who do **I want** to be **now**?

9. Debra remembered a tool she had studied. It was created by a famous psychologist named Abraham Maslow. It is a pyramid of the different needs people must address to feel happy and fulfilled. The needs at the bottom of Maslow's pyramid are basic ones: do I have the food, water, warmth, and rest my basic needs? Am I safe from harm?

10. The middle level of needs are psychological. Do I have strong relationships with family and friends? Do I feel accomplished and proud? The very top of the pyramid relates to self-fulfillment: do I feel creative and powerful? Do I feel like my best self?

11. Right after her stroke, Debra was at the bottom of the pyramid. She was completely dependent on the hospital and other people to keep her alive and safe. Nothing else mattered. As her health became more stable, Debra hated that people always had to help her. Her desire to be independent motivated her.

12. Meeting her psychological needs was harder. Without the ability to speak Debra's relationships changed. She had to find new ways to create meaning and be happy. She needed to build a different life with the abilities and limitations she had now. Debra was a teacher without words. But maybe she could teach in new ways. She could still inspire people. She could still share knowledge. With help, she could even write another book.

Chapter 3 Points for Reflection: A Teacher Without Words

1. Debra feels her identity was changed a lot by her stroke. How much do **you feel your identity** was **changed** by your stroke?

Very Little				Some					A Lot
1	2	3	4	5	6	7	8	9	10

2. What **parts of your identity** and life were changed by your stroke? (circle all that apply). What changed **the most**?

Family Friends Career

Home Life Hobbies

My Dreams What I Value Something Else

3. Manny worried that he could not be a good father and protect his family after his stroke. Were **you worried** about your family and friendships after your stroke?

Very Worried				Somewhat Worried					No Worries at All
1	2	3	4	5	6	7	8	9	10

4. Debra worked very hard to recover. It was very **important** to her to be **independent**. Was **regaining independence** a high **priority to you**?

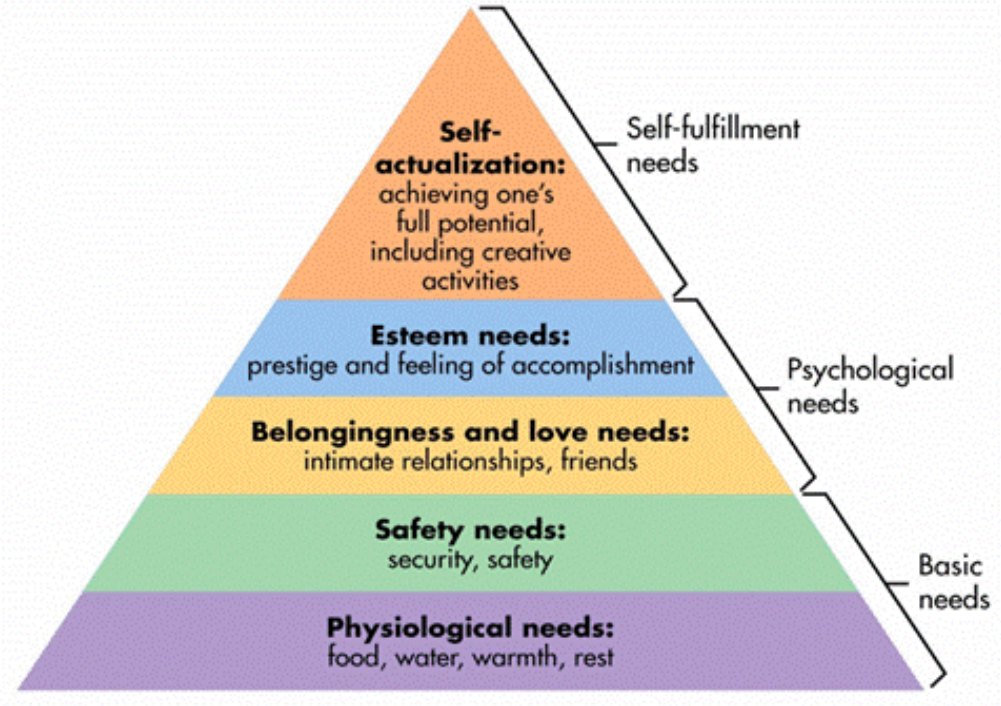
Not at All				Somewhat Important					Very Important
1	2	3	4	5	6	7	8	9	10

5. How would you describe your identity **when you were a child**? (For example: I was a son/daughter, I was a brother/sister/only child, I played sports, I studied hard, I liked to tell jokes…)?

6. How would you describe your identity **before your stroke**?

7. How would you describe your identity **after your stroke**?

8. Debra describes Maslow's Hierarchy or pyramid of needs. How high on the pyramid were you **before** your stroke? (Mark with a "**B**") Where are you now **after** your stroke? (Mark with an "**A**")



9. Debra felt very frustrated and scared when she was told she could longer be a professor. Did you have a **similar experience** after your stroke? What were you told or happened that made you feel this way?

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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?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 5 Summary: The Grind of Therapy

Four months after her stroke, Debra said her first spontaneous word outside of therapy. She popped out with the word “Babe” when her family tried to remember the movie name. Debra and her family were excited. This was the first time Deb had on her own generated a word without a prompt. It felt like a breakthrough moment. Most of her recovery has been slow and steady.

Debra worked harder than she was told to after her stroke. She believes that the word recovery does not mean just passively letting the body heal. It is rigorous work and training. She still goes to multiple therapies and starts every day with exercises. She feels that even when full recovery is not likely, therapy continues because small improvements are worth fighting for. It is a grind, but there are moments of inspiration.

Working hard every day is difficult. Debra shares the stroke recovery story of Intel executive **Sean Maloney**. Sean also worked nonstop after his stroke, saying it was the “hardest full-time job” he’s ever had. Since stroke recovery is often unpredictable, positive thinking is really important. When Sean heard a doctor say he’d never row again, he made his wife stop at the rowing club. He took his boat out, and even though he rowed mostly in circles, he had to prove to himself he could do it. Both Debra and Sean learned that it is important to celebrate small wins. Small wins are the little victories that can keep you motivated. These **small wins add up to big changes**. She now sees this recovery process as a marathon, not a sprint.

She tells the story of veteran **Jim Indelicato**. He led an active life pre-stroke. Jim lost his vision, balance, and the ability to walk, swallow, read, and breathe. Like Debra and Sean, he also worked hard to recover. His medical providers said he was “crazy,” but Jim was still determined. Even if he is not where he was before his stroke, Jim has come a long way. His wife believes his attitude has played a big role. Now, he works to motivate other survivors and therapists. He still lives an active life and focuses on the small wins.

Chapter 5 Highlights: The Grind of Therapy

1. Debra's family was eating breakfast one morning. They were talking about movies and could not remember the name of one. When Debra said "Babe," they were all shocked and excited. This was her first word outside of therapy.

2. This was a rare and dramatic breakthrough moment. Most of the time Debra's progress is slow but steady. Sometimes she does not notice improvements until someone sees her after a long time.

3. Rehab is a full-time job after stroke. Recovery means time and rest, but also rigorous work and training. It is a grind: hard and dull work that is important. Progress can seem small, but it is worth fighting for.

4. All she wanted at first was to get back to her old life. Even when Debra was not in therapy, she worked on rehab on her own.

5. Debra learned was that no one had answers. Her doctors could not tell her what was good or expected progress. This looked different for everyone. It was difficult for her to stay positive without these answers.

6. One way she and other survivors stay positive is by focusing on small wins. It is easy to see the big picture and forget the progress. Celebrating these small changes is important for mental health. They can also help survivors motivate each other through the grind of therapy. Recovery is now part of her identity.

7. She talked about stroke survivor and Intel Executive **Sean Maloney**. He said that therapy was the "hardest full-time job he'd ever had." After his stroke, he also wanted to go back to his old life. Sean worked on therapy 7 days a week, but realized it was okay to take days off.

8. Sean was angry when he overheard the doctor tell his medical team that he wouldn't row again. He made his wife stop at the rowing club on the way home. He needed lots of help, but he got the boat in the water. He mostly rowed in circles but had to prove to himself that he could do it.

9. Debra also learned that just doing more wasn't enough, form counted. She needed both determination and discipline. She had to do the exercises right. She and Steve developed the motto: ***Sometimes you have to go slow to recover fast***.

10. Debra spoke of a survivor named **Jim Indelicato**. Jim had been a fitness instructor in the military. He had a very bad stroke in 2010. He lost his vision, balance, and the ability to walk, swallow, read, and breathe. When he left the hospital after many months, he was on a feeding tube, a trach, and a ventilator at night.

11. He did not let this stop him and focused on small wins. It took several different approaches, but four years later, he ate his first solid food and then got off the ventilator. He surprised his doctors over and over again. Today, Jim is able to lead an active life and motivate other survivors. He looks not at his losses but all he has gained back.

12. Debra made working hard at recovery a priority but says it's important to regain other elements of your life. She advises that "time for friends, family, other activities, vacations, and joy have to be built alongside the rehab."

13. Debra, Jim, and Sean were all warned of the 12 month plateau –when progress would level out. They all found it to be a myth. Debra says, "It takes determination and creativity, but progress does not stop after twelve months."

14. Debra, Jim, and Sean all recognized that rehab was a long process. Sometimes they would even take a step backward. They see each step as another small win to be celebrated and remember how far they have come.

Chapter 5 Points for Reflection: The Grind of Therapy

1. Debra wanted to return to her old life after her stroke. She worked harder than she was asked in the first years. Did you set **extra practice goals** for yourself after your stroke?

Never				Sometimes					All the Time!
1	2	3	4	5	6	7	8	9	10

2. Debra learned that focusing on other parts of her life **outside** of rehab was important. She now takes days for her loved ones and fun activities. How important is building in time for people and things that bring you meaning, relaxation, and fun?

Not Important				Somewhat Important					Very Important
1	2	3	4	5	6	7	8	9	10

3. What are some areas **outside** of therapy that you like to focus on?

Family Hobbies

Music Friends Vacations

Sports Other

4. Debra talks about the importance of having both **determination** and **discipline** during recovery. Have you been able to find a **balance** between the two?

Not at All				Sort Of					Definitely
1	2	3	4	5	6	7	8	9	10

5. Debra and her husband Steve have a motto, "Sometimes you have to **go slow** to **recover fast**." How do you feel about this statement?

Disagree				Somewhat Agree					Strongly Agree
1	2	3	4	5	6	7	8	9	10

6. It is hard to know how progress should go after a stroke. Doctors may not have the answer. Debra worried about how her progress **compared** to other survivors. Was this something you experienced?

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

7. Debra, Jim, and Sean all learned to focus on the "small wins". What are some **small wins** that you are **proud of**?

8. Debra says that celebrating **small wins** is important for mental health. She also says that it can help motivate other survivors to continue with rehab. Is there a **story** that has **inspired** you? Or what keeps you **inspired?**

9. There is a myth that progress post-stroke stops after 12 months. Debra explains that this is **not true** at all. Share some examples of progress that you have made **past** the 12 month mark?

10. When asked what he would like to be remembered as, Jim said "Don't let anyone say I was lazy." What is something you want to be **remembered** for?

11. What **memories** of your journey with rehab has this chapter reminded you of?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 6 Summary: Let Me Talk!

Two years post stroke, Debra still avoided most big social gatherings. She decides to attend Steve's college reunion. As a professor, Debra had researched the impact of philanthropy on charter schools. When a discussion on charter schools arose at the reunion, she wanted to share her expertise on the topic. She couldn't find the right words to express her thoughts. Steve saw her frustration and helped to change topics.

Debra describes how aphasia's impact on speaking, understanding, reading, writing differs for each stroke survivor. Her challenges are mostly expressive. She struggles to express her thoughts, both speaking and writing. Even though she can construct ideas, words, and even sentences in her head, they often don't come out correctly. Debra shares how aphasia has changed her life more than her limp and lost use of her right arm. Aphasia forced her out of teaching and altered many of her core roles and relationships in life. Her family often played games of twenty questions to help guess her message. But they couldn't always figure out what was in her head. Debra is grateful that her thinking is still clear. Social relationships and identity rely heavily on using language. Aphasia can make you feel isolated and withdrawn.

Debra introduces **Trish Hambridge**. Trish was just 45 years old when she had her stroke. Her aphasia kept her from returning to the job she loved as a tech manager. She was known for her sense of humor and found new ways to express this to others. Trish is a tech pro who uses apps and other tools to help her communication. She is determined to continue life as best as she can. Debra tells the stories of several other people to highlight how different aphasia can be for each person. **Sean Maloney** tells how running his company with 15,000 people was "nothing compared to not being able to speak" and the demands of relearning speech. Debra has learned that continued determination and work is key. She says that those who say recovery stops

after 12 months are “flat out wrong”. But even with progress, having aphasia is a constant battle that requires adaptation in how you approach your life. Not being able to share all the expertise she holds in her head or what she cares about, has changed how she relates to people. Yet, relationships are critical to your identity. Debra emphasizes the importance of learning to communicate nonverbally and using other tools. Each person has to find their own set of strategies to help communication. Debra tells how Trish decided to go back into the world. She’s learned to be hilarious again using new tools.

Chapter 6 Highlights: Let Me Talk!

1. Two years after her stroke, Debra still tended to avoid big social gatherings. But she decided to go to Steve's college reunion. One conversation with a group of friends turned to charter schools. Debra had researched this topic as a professor. She could not join the debate and became very frustrated.

2. Aphasia's impact on speaking, understanding, reading, writing differs for each stroke survivor. It's different for each person. Debra says her challenges are mostly expressive. She struggles to express her thoughts, both speaking and writing.

3. Even though Debra can think of words, and even sentences in her head, they often don't come out correctly. Steve described in a CaringBridge post how painful it was to watch Debra's frustration when the wrong words came out.

4. Her family ended up playing many games of twenty questions to help figure out Debra's message. Sometimes they couldn't get to the answer. Her family challenged her to correct her errors when talking together. For Debra, conversation is not only about relationships, but also another focus of rehab.

5. Debra shares how aphasia has changed her life more than her limp and the loss of use of her right arm. Aphasia forced her out of teaching and altered many of her core roles and relationships in life.

6. Debra points out that there are about 2 million people in the U.S. who have aphasia, but it's still little known to the public. She cites speech pathology researcher, Dr. Leora Cherney and colleagues who report, "Those affected by aphasia report social isolation, loneliness, loss of autonomy, restricted activities, role-change, and stigmatization."

7. Although aphasia is a loss of language, not intelligence, the public may not understand. Debra warns that strangers may look at people with aphasia as incompetent, drunk, or childish when they first meet. But Debra is grateful that people with aphasia can still think clearly.

8. Debra explains how important our social relationships are to our identity. But these relationships rely heavily on language. Having aphasia can make one feel cut off from the world.

9. Debra introduces **Trish Hambridge**. Trish was just 45 years old when she had her stroke. Her severe aphasia kept her from returning to the job she loved as a tech manager at Apple. She was known for her sense of humor and practical jokes. She had a close group of friends.

10. Trish was determined to find new ways to express her humor and connect with people. Trish is a tech pro who uses apps and other tools like her cell phone to help her communication. Debra says Trish "owns her identity as an aphasic stroke survivor." She will tell a busy waitress that she has a speech problem, and the waitress will slow down. Trish is determined to continue life as best as she can.

11. Debra shares the stories of several other stroke survivors. Aphasia looks very different for each of these people. **Laura Wang** has the most extreme example of lost communication due to locked-in syndrome. Her language is still intact, but she can't move anything except her eyes. She uses a laser pointer and alphabet board to spell out what she wants to communicate. It is a slow and tedious process.

12. **Sean Maloney**, the Intel Executive, said that learning to speak again was the "most difficult experience" he has ever had. He said running his company with 15,000 employees was "nothing compared to not being able to speak." Both Sean and Debra benefitted from intensive Melodic Intonation Therapy which uses rhythm and melody to help regain speech. Debra also practiced hundreds of Rosetta Stone lessons.

13. Debra has learned that continued determination and work is key. She says that those who say recovery stops after 12 months are "flat out wrong." Progress may feel slow, but Debra's friends who don't see her often can see changes over time.

14. Having aphasia is a constant battle that requires adaptation in how you approach your life. Debra stresses the importance of making deliberate choices. Think about choosing quiet restaurants, small groups instead of big parties, having patience, and compassion for yourself.

15. Not being able to share the expertise she holds in her head or what she cares about, has changed how Debra relates to people. Yet, relationships are critical to your identity. It's vital to find ways to interact and share your values despite the aphasia. Using tone and gestures can help get a message across.

16. Debra quotes speech pathologist and researcher, Barbara Shadden, “If aphasia came with a warning label, I think it should read, ‘Hazardous to identity’.” Debra emphasizes the importance of learning to communicate nonverbally and using other tools. Each person must find their own set of strategies to help communication.

17. Debra tells how Trish decided to go back into the world. Trish misses not being able to quickly crack a joke. But she has learned to be hilarious again using new tools.

Chapter 6 Points for Reflection: Let Me Talk!

1. Debra said she avoided large social gatherings the first couple of years after her stroke. How do **you feel** about **large social gatherings**?

Dislike Going — So-so — Enjoy them!

1 2 3 4 5 6 7 8 9 10

2. Debra quotes another stroke survivor from an article who says, "**When I'm home alone, I don't have aphasia**." Do **you feel** this way, too?

Never — Sometimes — Often

1 2 3 4 5 6 7 8 9 10

3. Since the on-set of your stroke, what aspects of your speech and language have **gotten better**?

Memory Comprehension

Speech Attention Reading

Writing Other

4. Language is an important tool for maintaining relationships. How has your **aphasia impacted your relationships**?

Negative Impact — Positive Impact

1 2 3 4 5 6 7 8 9 10

Created with the generous collaboration of BU Aphasia Resource Center and CAL STATE EAST BAY SPEECH, LANGUAGE, & HEARING SCIENCES APHASIA TREATMENT PROGRAM

5. Debra says that those who say recovery stops after 12 months are "flat out wrong." Have **you** seen **continued progress** past the one-year mark?

No Progress				Some					Ongoing Progress
1	2	3	4	5	6	7	8	9	10

6. What is the **most frustrating** aspect of your **post-stroke challenges**?

7. Adapting and building your own strategies is important for communicating with aphasia. Describe some of **your adaptations** and **strategies**.

8. What was your **most important** take-away from this chapter?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 7 Summary: Grief

Debra recalls the shock that she felt when her father died suddenly in 1995. She did not know it then, but she was on the border of depression for several years. These feelings of grief resurfaced in 2013, when she learned that she could not return to work and would need to give up her tenured professor position at Stanford. After 3 years of working hard to recover and return to work, she was devastated. She felt she had failed. She knows now that she was grieving the loss of her own identity.

Most of the survivors Debra spoke to experience some level of depression, which can be triggered by physical damage to the brain as well as emotional trauma. Depression is one part of the **Kübler-Ross 5 stages of grief**: ***denial, anger, bargaining, depression,*** and ***acceptance***. Debra shares the story of **Malik Thoma**, CEO of a chain of day spas, who had a difficult time accepting his post-stroke status. He felt like life had no meaning and was often in the anger stage of the grieving cycle. Working towards some level of acceptance can assist survivors with looking forward to the future, rather than looking past to the old self. Debra says that optimism can feel extremely difficult but small wins, conscious choices, and finding new ways to live a meaningful life can benefit someone's post-stroke life.

Debra mentions how taking a small dose of an antidepressant medication helped with her anxiety while speaking. She promotes the benefits of therapy for stroke survivors. Many survivors with depression do not receive treatment for it. This can make it difficult for survivors to process the grief and damage that occurs to their identities. Many therapists are not specially trained to assist people with aphasia. When survivors do find qualified counseling services, the cost is often very expensive. This makes it hard for most people with aphasia to discuss their grief with a therapist. Some people turn to faith to battle the grief, and Debra uses meditation. Drawing on deeper values can lead to "post-traumatic growth"—growing past your grief. It takes the right attitude and support.

Chapter 7 Highlights: Grief

1. In 1995, Debra's 64 year-old father drowned in his backyard pool. She was in shock. Debra looks back on that time realizing the intense grief she was feeling.

2. She felt similar grief in 2013, when she was told she could not return to Stanford as a tenured professor. After working on rehab for 3 years, she felt she failed. She cried, stared into space, and punched pillows. She was grieving the loss of her old identity.

3. 1 in 3 stroke survivors experience depression, and nearly all the stroke survivors Debra spoke to experience some level of depression. It can be due to physical damage to the brain, emotional trauma, or both!

4. Survivors cycle through the 5 stages of grief: ***denial, anger, bargaining, depression,*** and ***acceptance***. It is common to move back and forth through the stages.

5. Debra acknowledges the difficulty and importance of striving for *acceptance*, which can ultimately help survivors live more fulfilled post-stroke lives. She stressed the challenge of looking forward instead of back at your old lives. Small wins, conscious choices, and finding new ways to live a meaningful life can help you get through grief.

6. She shared the story of **Malik Thoma**, CEO of a chain of day spas, who had a stroke and experienced a very difficult emotional journey. He did not have aphasia and could walk, but was highly discouraged, contemplated death, and often was in the ***anger*** stage. He could only focus on his losses. He felt let down by his family and was unable to find purpose.

7. Debra notes that stroke survivors adapt better if they recognize when they are in a "chaos" narrative. They can try to seek rebuilding and growth vs. thinking of pre-stroke abilities. **Laura Wang**, with locked-in syndrome, found meaning in her new life.

8. Due to performance anxiety around her speech, Debra takes a small dose of an anti-depressant. It is very helpful. Many people go without treatment for depression.

9. Stroke survivors often don't have access to skilled counseling services to address the emotional challenges after a stroke. These services are rarely available and can be very expensive. It is very hard to find a counselor trained to help clients with aphasia.

10. Debra feels that given the biological and emotional impact of stroke, psychological support should be a standard treatment option, just like physical, occupational, and speech therapy.

11. As an alternative, some people can process their grief through faith and religion. Debra processes her grief using meditation practices.

12. At the end of the chapter, Debra discusses how psychologists often describe two paths people take in trauma recovery. People either go the route of depression and PTSD, or the other route of recovering and "bouncing back."

13. A third route is mentioned, which is the path of "post-traumatic growth." You get through the grief and grow past it. This is the route Debra believes she has taken in her stroke battle.

14. Debra ends the chapter with a favorite line from the book *Option B* by Sheryl Sandberg and Adam Grant that describes how to recover from grief: “Life is never perfect. We all live some form of Option B. This book is to help us kick the shit out of it.”

Chapter 7 Points for Reflection: Grief

1. Debra mentions the **5 stages of grief**, and she says that not all survivors experience all stages. Which stages have you experienced in your stroke journey?

Denial Anger Bargaining

Depression Acceptance

2. Debra says that it is a challenge to **accept your post-stroke self**. How much of a challenge has it been to accept the post-stroke changes in your life?

Not Challenging				Somewhat Challenging					Very Challenging
1	2	3	4	5	6	7	8	9	10

3. Debra was devastated to learn that she would not return to work despite her 3 years of progress. Have you ever **received news** that you did not expect along your recovery journey?

Not at all Occasionally Frequently

4. Have you ever found it challenging to **stay optimistic** during recovery?

Not Challenging				Somewhat Challenging					Very Challenging
1	2	3	4	5	6	7	8	9	10

5. Debra mentions that **adequate psychological support** from therapists can be expensive, which can make it hard to process emotional grief after stroke. What has been your experience with this?

6. In the book, Debra says that for some, turning to faith is a critical part of recovery. Describe the sources where you have **found emotional support** (such as faith, religion, or meditation)?

7. Looking back on different parts of your recovery journey, were there any points in which you experienced "**post-traumatic growth**?"

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

Chapter 8 Summary: Lean On

During Debra's stay at the hospital, her husband Steve read letters to her from family and friends. Debra admits that she was known for being independent and stubborn before her stroke. Even though Debra was feeling a lot of anger and fear, she also felt a growing sense of gratitude for the strong community of support. Studies have shown that strong support networks are linked with better mental well-being and physical recovery. After Debra's stroke, her friends dropped off pre-cooked meals and continued with deliveries for many months. Since a stroke can be isolating, being surrounded by loved ones helps with confidence, motivation, and the ability to focus on the values that matter most. Stroke survivor **Kathy Howard** was insecure about attending a high school reunion. Her friend convinced Kathy to go despite her fears. Kathy had a great time. Kathy shared with her old friends that she was attending a stroke awareness walk the next day. Kathy was surprised when about 20 people from the reunion came to support her at the walk.

Unlike Kathy Howard, many stroke survivors feel like they have no support. **Mary Jones** was placed in a retirement home by her family at the age of 44. Survivors are not always encouraged to seek out support groups, and some families do not have access to training or resources. Insurance rarely covers emotional therapies. Debra also explains how stroke survivors need the right kind of support. She recommends that friends offer to help with specific tasks instead of asking in general "how can I help?"

It has been a process for her to learn to accept help. Debra reflects that while it is important to acknowledge her stroke, she didn't want it to be the only focus of the interaction. She explains that being a stroke survivor is only one part of her identity. Debra refers to psychologist **Susan Silk's ring theory for trauma supporters**. The center ring is the person directly impacted–the survivor. The people next most affected, and often most able to support the survivor are in

the second ring. In the next ring are the people most able to support those in the second ring. Then you keep drawing bigger rings and writing the names of the next group of people most affected by the loss. Susan suggests, wherever you are in the circle, to “offer comfort in and seek comfort out” for a strong, sustainable support system.

Chapter 8 Highlights: Lean On

1. Debra's husband Steve continues to read supportive comments and letters from friends and family to Debra while she is in the hospital. Her support network strengthened Debra's determination to keep pushing forward.

2. Debra realized that although she felt a lot of anger and fear at first, her life is what it is today because of her support system. Studies find that social support has a positive impact on our psychological well-being and physical health.

3. These networks can help with everyday tasks which allows the stroke survivor to focus on recovery. It also helps the family. For example, one of Debra's closest friends, Kim, organized a food team. They dropped off precooked meals. Many of these friends continued deliveries for months after Debra's stroke.

4. Debra talks about stroke survivor **Kathy Howard**, who felt insecure about her disabilities and did not want to attend a high school reunion. A close friend persuaded her to go. Kathy ended up having a great time.

5. She told her old friends that she was attending a stroke awareness walk the next day. She was surprised when many people from the reunion came to support her at the walk. Kathy's friends provided a supportive and encouraging environment for her.

6. Debra admits that it is hard to accept help when you are used to being independent. Embracing help did not come naturally. She wanted to do as much as possible on her own. Over time, she came to feel gratitude for being able to lean on a strong network.

7. Debra shares that after her stroke, she felt embarrassed and a burden at times. She notes other stroke survivors often experience similar feelings. Once Debra opened up and overcame her fears, she noticed how ready people were to help her and she could accept their support. She realized that life with a strong support network was beneficial.

8. Organizational behavior faculty and graduate students from around the country attend "May Meaning Meetings." These meetings focus on how to make a difference through meaning, and Debra loved to attend before her stroke. The 2014 May Meaning Meeting was the first academic event she attended after her stroke.

9. She used her "Lucky to Be Alive" speech and added a section on the book idea. Those who attended pushed her to commit to the book project and helped her find more meaning in her poststroke self.

10. Unlike Kathy Howard, **Mary Jones** was one of the stroke survivors who did not have a strong support system. After her husband divorced her, Mary's family placed her in a retirement home at the age of 44.

11. Debra points out that many U.S. stroke survivors also feel they have little or no support. Unfortunately, survivors are often not encouraged to seek out support groups. Families also have little access to training or resources to help support the stroke survivor.

12. Debra has leaned on her support network for 8 years. She has learned what makes support effective. Friends who ignored the situation made her feel isolated. Debra explains that it is important to acknowledge the stroke, but to not make the interaction completely about the stroke. Being a stroke survivor is only one part of her identity.

13. Debra points out friends mean well, but do not always know how to help. She advises offering to do a specific task rather than asking in general what you can do to help. Debra explains that this saves the stroke survivor energy and the discomfort of making a response. For example, their friend Kevin said he would just install a left-side handrail for their stairs after confirming it would help with Debra's return from the hospital.

14. It is common for social networks to fade over time and become smaller. Psychologist **Susan Silk** developed a **ring theory for trauma supporters** to keep a sustainable support system. The center ring is the person directly impacted–the survivor. The people next most affected, and often most able to support the survivor are in the second ring. In the next ring are the people most able to support those in the second ring. Susan suggests, "Wherever you are in the circle, offer comfort in and seek comfort out."

15. When there is not a strong enough support system, people may need to take the situation into their own hands. Mary, for example, moved herself out of the retirement home and into her own apartment. She then found herself a strong support system in a church in St. Louis. Mary has moved up to higher needs in Maslow's pyramid. She can now build a true sense of belonging in her chosen community.

16. Recovery from stroke is a long journey. Debra shows her gratitude for the overwhelming amount of support she and her family have received from both friends and family.

Chapter 8 Points for Reflection: Lean On

1. Mary Jones had to take her situation into her own hands and help herself because she did not have a strong support system. Did you ever have to **fight for yourself** to get **better resources** or **support**?

Not at all Occasionally Frequently

2. Kathy Howard at first felt insecure about going to reunions and seeing other people because of her **post-stroke disabilities**. Have you felt **insecure** about **people seeing you** after your stroke happened?

Not at all Occasionally Frequently

3. Despite her fears, Kathy had a great time at her reunion. Have you ever felt **unsure about joining** an event, but realized afterwards that it was a **good idea that you tried it**?

Disagree Somewhat Agree Strongly Agree

1 2 3 4 5 6 7 8 9 10

4. Debra also mentions that many families **lack** the necessary **resources** and **training** to **efficiently support** a **stroke survivor**. How much **training or resources** did **your families, carepartners, or caregivers receive** after you had your stroke?

Nothing Some, not enough A lot; enough

1 2 3 4 5 6 7 8 9 10

5. Debra notes that some people either make the situation **all about** the stroke or **completely ignore it**.
Have you felt that people you know have acted like one of these **extreme sides**, either **ignoring it** or making the situation **all about** the stroke?

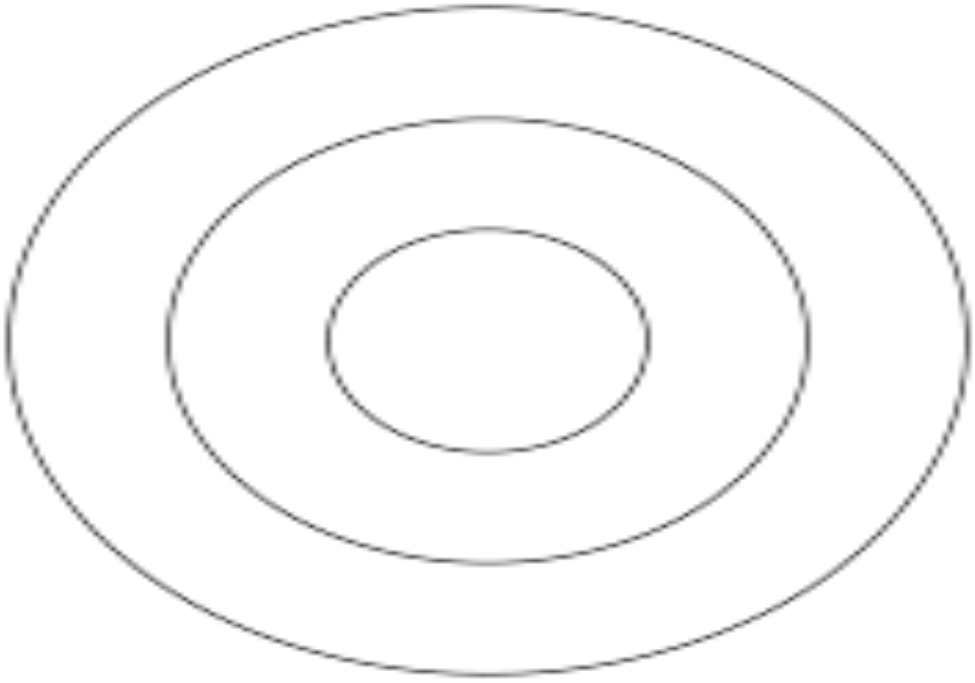
Not at all Occasionally Frequently

6. Debra explains that making specific suggestions on how to help is **better** than asking a stroke survivor "What can I do to help?". What are some **concrete ways** people have helped you after your stroke?

7. When Steve would read Debra all the **supportive messages** from family and friends, Debra became **more determined and enthusiastic** to push through, especially immediately after her stroke. What **helped you** get through those **first few months** of your stroke?

8. Debra points out that stroke survivors are often **not encouraged** to seek out **support groups**. How and when did you get connected to a stroke group? What was your experience like? What were the benefits for you or your family?

9. Susan Silk's theory suggests that the stroke survivor is in the center of a ring of circles, with those next most affected, and most able to help the survivor, in the next circle and so on. Write **your** name in the middle circle. **Who** would you consider to **be part** of your second ring? And in the third ring, most able to help them??



10. Share **your most valuable take-aways** from this chapter about learning to accept help and support networks.

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 9 Summary: Stroke Is a Family Illness

Two years after her stroke, Debra's daughter Sarah gives a speech at her high school. Debra and her husband Steve come to listen. The speech is about Sarah's journey since her mother's stroke. She describes the night of the stroke and the initial years that followed. Right after Debra's stroke, Sarah did not want to reach out for help from friends or teachers. She was afraid that if she did, people would think she was weak. Once she finally opened up to her friends, she felt free. It is not only the stroke survivor that needs help. Those who are close to them need support, too. Sarah learned that asking for help is a sign of strength, not weakness. She ends her speech by saying, "no matter how much you can bench press, you always need a spotter." This is the first time Debra had heard of her daughter's suffering. She and her husband cry during and after the speech. Debra describes that her tears were in pain hearing about how difficult her stroke made Sarah's formative high school years. She also describes her tears as tears of joy because she realizes that Sarah had "found a way to bounce forward."

Debra talks about ways that entire families are affected by stroke. The way that families are affected changes as time goes on. At first, the family members rally together to get through trauma. This theme is called "**the family as a lifebuoy**." There is also a gap created in the family. This gap takes the place of the role the stroke survivor played. This theme is called "**absent presence**." The gap can shift the roles of every family member, leading to "**broken foundations**." Roles need to be adapted in order to navigate the change together. Changing roles allows families to "**find a new path forward**." The family takes on a new identity. Tremendous effort is required by all family members. One person's stroke affects everyone. Many carepartners experience depression. In this way, "**stroke is a family illness**." The work cannot fall on one family member. Everyone needs to help. Debra discusses how the roles in her family changed after her stroke. Steve became her

primary carepartner. He was always optimistic and patient. Her son Adam took the role of peer. Her son Danny, who was in college, visited home more often to be with her. Her high school daughter, Sarah, took on a more adult role. Debra realizes how important it is to play the role of Sarah's mother again.

Debra shares the experience of **Malik Thoma**, CEO of a chain of day spas, whose family relationships were damaged soon after his stroke. Malik felt that some of his family members overstepped their bounds in their efforts to manage his medical care. Debra writes that Malik struggles to think positively about his recovery and this may be because of the bitter relationships with those who were once closest to him. She also writes about the experiences of **Mary Jones**, whose husband struggled to find a new path forward after being a carepartner for 3 years. He sends Mary to her family who put her in a retirement home. Debra notes that neither Malik nor Mary had large families nor close communities and that collapse is more likely when dependence falls upon one person.

Debra writes about all the new roles that her husband Steve takes on after her stroke: *primary carepartner, emotional coach, motivator, health-care navigator, financial manager, chief logistician, rehab equipment engineer and communicator to family, friends and even her colleagues*. She also shares the importance of the critical support that Steve received from extended family and friends.

As family roles change, Debra writes that stroke survivors must wrestle with their own changing role, which for many of us is a critical aspect of our life and identity. She shares the experience of **Manny Gigante**, who had a stroke at 29 and who initially struggled with his role as a father to his sons. Manny comes to the conclusion, "… mentoring or parenting my son doesn't necessarily mean I have to be in that physical role. I can coach him in ways to be a good person and good human being, not just being a good athlete."

Debra shares the story of **Whitney Hardy**, the daughter of her good friends Molly and Tom. Whitney is a few years older than Debra and Steve's son Adam. While still in her 20s, Whitney was struck by a car and suffered a severe traumatic brain injury (TBI) a few months after getting engaged to her college boyfriend, Dan. While Dan stays by Whitney's side for three years during her recovery, he ultimately breaks off the engagement. While this is devastating for everyone, Whitney's family is grateful to Dan for all of the support he gave to Whitney for those years.

Soon after Sarah's speech at her high school, Steve pushes Debra to step back into her mothering role. Sarah was planning to attend her Senior Prom and Steve suggests that Debra have "The Talk" with her. Despite Debra's limited speech, she initiates the mother-daughter sex education "Talk" by saying:

> Boyfriend …[long pause]...
>
> "Yeeessss?" (voice rising, half statement, half question)
>
> …[very long pause… then rapid explosion of breath and words]… PREGNANT NO!!!!

After a lot of laughter, all agreed that Debra has delivered the most efficient "mother-daughter talk" in history.

Chapter 9 Highlights: Stroke Is a Family Illness

1. Debra's daughter Sarah gives a speech to her entire school about her journey in the years following her mother's stroke. Debra and her husband Steve are in attendance.

2. Sarah shares in her speech details of her mother's stroke, and how she herself struggled to reach out for help after it happened. She worried that she would be seen as weak if she told her friends how much she was struggling.

3. Once she finally opened up to a friend, she said she felt free. Her friends "lifted her up from the bottom of the pit." Peers she did not know well even offered to help.

4. Like her mother, Sarah discusses the "silver linings" of the stroke. There has been more family time, her mom laughs more now, and Sarah learned to asked for help. She ends her speech saying, "As every athlete knows–no matter how much you can bench press, you always need a spotter."

5. This was the first time Debra had heard about how much her daughter struggled after her stroke. Both Debra and Steve cried tears of pain and of joy during and after their daughter's speech.

6. Debra discusses how "**stroke is a family illness**," affecting every family member. She describes **four themes** that are **found in post-stroke families**, discovered in research done by Gabriele Kitzmüller.

7. The first theme is titled "**the family as a lifebuoy**." This arises immediately after the stroke, when the whole family unit comes together to help the stroke survivor.

8. The theme "**absent presence**" describes how the role of the person in the family who had the stroke is now vacant. For example, Debra's role as mother and wife in her family completely changed immediately following her stroke.

9. "**Broken foundations**" refers to how everyone's role in the family changes post stroke. Every member of the family takes on new roles in order to adapt to the new normal they have found themselves in.

10. Finally, the family starts "**finding a new path forward**." This involves each family member working within their new role to make the new family dynamic work.

11. Debra describes the experiences of different stroke survivors and the effects that their strokes had on their families. The family support and reaction to their strokes varied greatly from person to person. The support that stroke survivors receive from their family can positively or negatively impact their recovery process.

12. She describes **Malik Thoma**, CEO of a chain of day spas, who struggled with the tensions in his family over his care. It left him with bitter feelings, and he has struggled to find a positive path forward.

13. Debra describes how her own family's roles changed after her stroke. Her husband, Steve, took on many new roles, including her primary carepartner. Her children all took on more adult roles than they had before, stepping up to help to provide their mother with a level of support that they haven't had to in the past.

14. Debra tells how **Manny Gigante**, who had his stroke at 29, worried about how he would be a good parent. He realized that "parenting my son doesn't mean I have to be in that physical role. I can coach him in ways to be a good person and good human being, not just being a good athlete."

15. Debra shares the story of **Whitney Hardy**, the daughter of a family friend who was hit by a car in her twenties. She suffered a traumatic brain injury (TBI). Her fiancé at the time supported her in her recovery, but eventually he decided he could no longer marry her.

16. Although this was devastating for the entire family, Whitney's parents were appreciative that he supported her as long as he did. They felt that his support made a positive impact on her recovery.

17. Sarah's speech made Debra realize she needed to start playing a more active role as Sarah's mother again. She decided it was time for her and her daughter to have "The Talk" before Sarah went to her senior prom.

18. With her limited speech, Debra's talk did not go as planned, but it was a positive experience for Sarah, Steve, and herself. Her bottom line was telling Sarah, "PREGNANT….NO!!!" They all laughed aloud together, and "agreed that she had just delivered the most efficient mother-daughter talk in history."

Chapter 9 Points for Reflection: Stroke Is a Family Illness

1. Debra talks about how her daughter struggled to deal with her stroke. How many of your family members have told you about how your stroke has **affected them**?

None | One | A Few | Most of Them | All of Them

2. Debra's daughter, Sarah, describes how she received so much **support** once she opened up about her struggling. How much **support** did your family receive from others after your stroke?

None — Some Support — A Lot of Support

1 2 3 4 5 6 7 8 9 10

3. Debra describes how important it is for family members to change their **family roles** in order to make things work after someone has a stroke. How much has it felt like the **roles in your own family have changed**?

Not at All | Somewhat Changed | Changed Quite a Bit | Completely

4. Steve is the person in Debra's life who took on the role of her **primary** carepartner after her stroke. Who in your life was the one to take on this role?

Partner | Child/Children | Parent/Parents | Friend | Someone Else

5. Debra says, "**When dependence falls on one person, collapse is far more likely. Support needs to be spread widely among family members**." Thinking about your own experience, do you agree with this statement?

Disagree				Somewhat Agree					Strongly Agree
1	2	3	4	5	6	7	8	9	10

6. Debra describes the experiences of other stroke survivors, and how their family's support (or lack thereof) affected their recoveries. **How do you feel that your support system affected your recovery?**

7. Sarah discusses in her speech the "silver linings" for her, her mother, and her entire family after her mother's stroke. Has your family found any **"silver linings?"** If so, what are they?

8. Debra describes how her role as a mother to her daughter has changed since her stroke. How has one of your roles or identities in life **changed** since your stroke?

9. Sarah shares her lesson: "I learned that asking for help isn't a sign of weakness but a sign of strength." Share at least one example where you decided to **ask for help**, even though it was hard.

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 10 Summary: Partners and Intimacy

Debra shares the challenges she faced with Steve and their relationship six months post stroke. Steve had regained a sense of normalcy in his life at work, whereas Debra did not. Debra experienced a constant internal battle about wanting to receive help from Steve and not wanting help. This resulted in frequent bouts of anger and resentment. Debra tried to show her appreciation. Steve learned he couldn't help support Debra if he put his own needs on hold. Debra knew she was actually mad at her situation and not at Steve, but it took a toll on their marriage. They would have to work hard to evolve their partnership.

Right after a stroke, the focus is almost all on the survivor. Not everyone has a partner, but for those that do this imbalance puts intense demands on the closest carepartner. It affects the relationship dynamic for many couples. **Julia Fox Garrison** and her husband struggled with her terrible mood swings and with role changes. Julia realized she wanted her husband to be a partner, not a nurse. They had to switch their focus to opportunities rather than limitations. **Malik Thoma**'s relationship with his wife plummeted, but their relationship was also strained before his stroke. **Randy Miller** and his wife Rose decided when it came to his recovery, "It's not one of us; it's both of us." Rose chose the term carepartner over caregiver. **Deidre Warren**'s physical disabilities remain significant, so she is dependent on her husband, Mike. Yet, Mike's anger is at the stroke, not Deidre. **Andrea Helft** struggled with body image issues and lost interest in sex. **Gail Rusch** lost her sense of confidence in her attractiveness but was reassured by her partner that he loved her for who she was now. Debra emphasizes that despite physical and mental challenges, sex lives can still be fulfilling for a couple post-stroke.

Aphasia continues to be the biggest challenge in Steve and Debra's relationship. It takes a long time for Debra to get her message out, so listening takes more patience. They both can get frustrated. But Debra appreciates that Steve is a "look forward, not backward" kind of person. They continue to work through their issues with honesty and as a team.

Chapter 10 Highlights: Partners and Intimacy

1. Six months after Debra's stroke, Steve was back at work. Debra's days revolved around as much outpatient therapy as possible.

2. Debra found frustration and resentment building. Sometimes Steve helped too much, other times not enough. He felt like he couldn't get it "right." This dynamic took its toll on their marriage's foundation.

3. Debra explains that a stroke will challenge a couple in caregiving, but also in every aspect of the relationship: emotional support, roles in the household, financial stability, attitudes, and sex.

4. After the stroke, most of the focus is on the survivor. The carepartner faces huge demands and changes in roles. This causes fear or interference with other obligations. Carepartners often put parts of their own lives on hold.

5. Kitzmüller and colleagues found in their research that many marriages did not survive the stress of the stroke. Sometimes the survivor did not want to limit their healthy partner's life, or their partner was unwilling to change their role in the relationship.

6. Almost 50% of all marriages in the U.S. end in divorce. Relationships are difficult and complex. It makes sense that after a stroke, partnerships will require even more work to evolve and thrive.

7. Stroke survivors who navigate their recovery without a partner face an even harder road.

8. Debra talks about different stroke survivors and their relationship and intimacy experiences:

1. **Julia Fox Garrison**: Julia faced challenges such as terrible mood swings due to her medications. This caused strains on her relationship, as well as the change in roles. She realized that she wanted her partner back as a husband, not as her nurse. They worked hard to figure out how to reconnect sexually as a couple.

2. **Malik Thoma**: After his stroke, the effect on his marriage was "devastating." He and his wife also struggled before the stroke. They seem stuck resenting each other instead of finding a new path forward.

3. **Randy Miller**: Randy and his wife Rose made a concerted effort to move beyond the patient and caregiver dynamic to make sure that their relationship would stay balanced. She decided to use the term carepartner instead of caregiver. Despite his severe aphasia, he managed to order flowers for their anniversary. They cherish time together, be it mowing the lawn or making love.

4. **Deidre Warren**: Deidre is dependent on her husband Mike due to her physical disabilities. Although her dependence can be frustrating, Mike is grateful that he has the ability to help Deidre. He feels the loss of their retirement plans. He is angry at her stroke, not her. Mike has also rediscovered what made him fall in love with his wife.

5. **Andrea Helft**: Andrea was a recreational athlete at the time of her stroke. Her stroke impacted her self-image and confidence in returning to intimacy. She lost her interest in sex.

6. **Gail Rusch**: Gail felt unattractive after her stroke which impacted her interest in intimacy. Her sweetheart's reassurance that he loved her as she was, changed her mind about intimacy and self-image. It is a good reminder that our identities are often influenced by those closest to us.

9. Kitzmüller's research promoted the value of peer groups where people can share common stroke experiences and expand their social network. Couples that thrived looked forward, not backward. These couples focused on opportunities not limitations.

10. Steve got good advice: he had to take good care of himself in order to take good care of Debra. Debra is happy to encourage Steve to do things he loves like skiing or long bike rides with friends. But she admits that she often misses getting to join him.

11. Debra points out that small gestures of appreciation can go a long way. She looked for ways to show Steve she cared and appreciated his efforts.

12. Steve and Debra have not pursued counselling since her stroke. They have pulled on insights and tools from the two other times they had counselling before her stroke.

13. Debra considers herself lucky that her enjoyment of sex improved after the stroke. She doesn't know why, but it's a silver lining. Steve thinks being less stressed helped her.

14. Debra says that emotional and psychological factors are often bigger barriers to resuming sex than physical limitations. Couples may wonder: "Is sex safe?", "Am I still attractive?", "Can I be both a caregiver and a lover?", According to the experts, even though you may need to make adaptations due to physical changes, stroke survivors and their partners can usually recreate a healthy, fulfilling sex life.

15. Researcher Meghann Grawburg from New Zealand reports that stroke survivors may report less frequent sexual intimacy. However, she found it was often replaced by other forms of physical intimacy, like more physical touching.

16. Aphasia remains the biggest ongoing challenge in Debra's partnership with Steve. Debra has challenges in expressing herself and it takes more patience to listen to her.

17. Debra explains that some of what helped her relationship with Steve was simply "good luck." He tends to be a "look forward, not backward" kind of person. He has a positive and problem-solving approach.

18. Debra admits that now and then, his positivity can drive her crazy. When she is struggling and mad at the world, it can feel like Steve doesn't see how hard it is. Debra and Steve still face challenges, but they work through those with honesty and togetherness, in an always evolving relationship.

Chapter 10 Points for Reflection: Partners and Intimacy

1. Debra explains that after her stroke she often directed **frustration** towards her husband even though she was mad at the situation and not at him. Did **you ever express anger** and **frustration towards a loved one**, even though they weren't to blame?

Never				Sometimes					Often
1	2	3	4	5	6	7	8	9	10

2. Debra states, "A stroke will challenge the pair not just in caregiving, but in every aspect of the partnership"(122). What aspects of your **relationship** have **changed**?

Financial
Responsibility Social Intimacy

Attitudes Roles Other

3. Debra explains that while you may need to make adaptations due to physical changes, stroke survivors and their partners can usually recreate a healthy sex life. Did **you** receive adequate **support** and **information** about **intimacy** and **sex after your stroke**?

Not at All				Some information					A Lot
1	2	3	4	5	6	7	8	9	10

4. Sometimes Debra wanted **more help** from Steve, other times she wanted **less help**. It was **hard for Steve** to know what to do. Have **you** ever found yourself in this **dilemma with your carepartner**?

Never Rarely Sometimes Fairly Often All the Time!

5. Relationships continually **evolve**. Are you still **learning** about what **works best for you** and **your partner** after your stroke?

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

6. In the book, Debra says that "Steve got good advice; he'd be no good as support for me if he didn't take care of himself." It is important for our loved ones to take care of themselves. What can you do to help your carepartners **take care of themselves**?

7. Debra says she's lucky that Steve is a "**look forward, not backward**" type of guy. Why is this a **helpful outlook** after stroke? **Describe** someone in your life who has this attitude.

8. Relationships are **complicated** and **difficult**, even without the stress of a traumatic event. After your stroke, did you feel like your relationships with loved ones **improved** or do you feel as though you are **less connected** to loved ones?

9. Debra tried to express appreciation to her carepartner in a variety of ways. What are some ways you have **expressed appreciation** to your main carepartner?

10. What was your **most important** take-away from this chapter?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 11 Summary: People are Social Animals

Seven months after Debra's stroke, her friend, Anne Payne, organized a trip to celebrate her birthday in Palm Springs. Debra said she couldn't go because of her limitations, but then her friend Kim Menninger convinced her to go. During the trip Debra often became frustrated because she could not participate in many of the activities and conversations. Sometimes she worried she was holding the group back. However, Debra also felt fantastic about being able to soak up the energy of friendships. She was able to get up and dance for the first time since her stroke. This made Debra realize how much she had been limiting herself by hesitating to rejoin the social world.

Social interactions play a key role in shaping our identities; yet most stroke survivors are reluctant to rejoin social structures that they once enjoyed. Stroke survivors' impairments can make interactions difficult and the emotional trauma and confusion can make them unsure about previous relationships. Stroke survivors may feel they are burdening their friends by forcing them to cope with their impairments. Debra has found through experience that close friends are usually willing to help and be patient.

Debra has encountered **six most frequent reasons** for stroke survivors' social hesitation. The first reason is **"I physically can't be social."** The second reason is "**it's too hard to be worth it.**" For so many, socializing after a stroke is harder and incredibly frustrating. The third reason is "**other people piss me off.**" It is hard to be in social situations where others around you display nonverbal clues that you are not welcome. The fourth reason is "**I'm a bother.**" Many of us feel frustrated at our lack of independence and extremely insecure about the perceived burden we place on others. For stroke survivors, social interactions take a lot more effort. Friendships change but many of us find that those closest to us are even more supportive than before. The fifth reason is "**I'm embarrassed.**" Often, we let ourselves be embarrassed by our new

circumstances rather then choose to embrace a new social identity. The last reason is "**I'm depressed.**" One in three stroke survivors suffers some degree of depression, which can leave you feeling isolated and frustrated. One of the most important ways to push through depression is an active social life.

Chapter 11 Highlights: People are Social Animals

1. People are fundamentally social by nature; we all need friends and a social life to be happy. Interacting with friends in social situations has positive benefits in helping to create your new identity poststroke.

2. This can be hard after stroke, and there are real reasons survivors reduce or avoid socializing such as depression or feeling embarrassed. Although it is difficult to socially interact, looking forward to time with your friends can be a positive experience.

3. But it is critical to overcome these barriers and reestablish a social life, whether with old friends or new ones. Even though your relationships with your friends may shift, you can still have meaningful interactions.

4. Social interactions are very important ways for survivors to experiment with and learn about our changing identities. Some find their social interactions with their friends to be a key part of their new identities which can be a shift from their pre-stroke identities.

5. Relationships may change, and some may fade, but others may emerge or become stronger than ever.

6. Joining a group with fellow stroke individuals can give you a safe zone to practice your speech skills. This is also a great way to meet new people and establish new friendships.

7. Once we commit ourselves to looking forward and creating a meaningful social life, we realize how many ways we can adapt. Debra's speech is better in the morning than in the evening when she's tired, so she tries to invite people over for brunch, not dinner.

8. One in three stroke survivors suffer from depression even if it is never diagnosed. One of the most important ways to push through mild depression is an active social life.

9. Andrea Helft states, "I think my stroke has improved me. I do. I think I'm happier and probably healthier—better in a lot of ways. I might even do it again if I had to. Isn't that crazy? I think my relationships are deeper, too." Although this level of optimism is uncommon, she enjoyed shifting her priorities to focus on fostering her relationships with family and friends.

10. Debra discusses a few stroke survivors and their experiences with social interactions:

1. **Laure Wang:** She is confined to a wheelchair and unable to move anything but her eyes. She decided to finally attend her high school reunion which helped in adjusting her attitude to her new life.

2. **Andrea Helft:** She struggles with significant memory issues and pain from her stroke. She received a lot of help and support from her friends which resulted in them gaining clarity in their own lives.

3. **Gail Rusch:** She lost her ability to work and to run and coach running. She enrolled in college, graduated in 2016, and this was a huge catalyst in the process of recreating her identity.

4. **Trish Hambridge:** She has gone on several vacations organized by the Aphasia Recovery Connection which have been particularly rewarding. She initiates contact with friends.

5. **Julia Fox Garrison:** She realized her recovery required a lot of positive energy and states, "I learned who is my real friend. I thank my stroke for helping me to cut out most of the negativity and negative people in my life."

11. Debra lists six reasons stroke survivors often give for limiting their social activities:

1) I physically can't be social
2) It's too hard to be worth it
3) Other people piss me off
4) I'm a bother
5) I'm embarrassed
6) I'm depressed.

12. Relationships serve as an important part of our identity with or without stroke recovery. They are powerful silver linings for most people going through stroke recovery.

13. "Identities are not simply features or products of the individual…They should be viewed as practices with others and the outcomes of those interactions." After stroke, we are in a process of rebuilding our sense of self and navigating a changing identity.

14. Steve's classmate Karen Jordan, who started helping out with their dog Kaya, offered Debra to walk with her weekly since that was part of Debra's new routine. Debra was touched by this because she knew Karen had a busy life. They are now close friends. This is yet another silver lining in Debra's life.

15. Once we commit ourselves to looking forward and creating a meaningful social life, we realize how many ways we can adapt. Debra was grateful when her colleague, Robin Ely, and her husband opened their home to her while she did a clinical trial in Boston. Their relationship has shifted. Debra realizes their bond and her identity is now more based on social connection than work.

Chapter 11 Points for Reflection: People are Social Animals

1. Why did they call this chapter **"People are Social Animals"?**

People are like animals.

People need social interactions to create their identities.

I don't know.

2. One in three stroke survivors **suffer** from **depression** even if it's never diagnosed. Have you also **struggled with depression**?

No Not Sure Yes

3. Most **stroke survivors** are reluctant to **rejoin social activities** that they once enjoyed before their strokes. Have you also been **reluctant** to rejoining social events? If yes, **why**?

I'm embarrassed

Physical limits

I feel like I'm a bother

Struggling with depression

Other

4. How did you feel the first time you rejoined a **social** event with friends **poststroke**?

Sad or frustrated — Somewhat frustrated — Fantastic

1 2 3 4 5 6 7 8 9 10

Created with the generous collaboration of BU Aphasia Resource Center and CAL STATE EAST BAY SPEECH, LANGUAGE, & HEARING SCIENCES APHASIA TREATMENT PROGRAM

5. How have your **social interactions** been with your **family** and **friends** poststroke? Have your experiences been **easy** or more **difficult**?

6. Debra created a new **friendship** with Karen by **walking together** on a weekly basis. What have you **experienced** in terms of new friendships since your stroke?

7. Debra talks about finding **silver linings** in her **stroke recovery**. What has been a silver lining for you since you had your stroke?

8. Are there any **social events** or interactions that have helped you adjust your **attitude** towards your **new life** after your stroke?

9. Debra lists **6 reasons** that stroke survivors (and also others with impairments or chronic illness) may use to avoid rejoining social activities. Describe which ones seem **most relevant** to your life:

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 12 Summary: How the World Responds

Six years after her stroke, Debra went on a week-long hike in Peru with her family. Most friends thought they were crazy to try such an ambitious trip, but Debra is stubborn and completing this trip would have great emotional significance. Toward the end of her trip, in Machu Pichu, Debra was walking down some steps with her walking stick. Suddenly, a group of people rushed by quickly, making it difficult for her to keep her safe position. Soon after, an older man reached out a helping hand to her. Debra wrote about the anger she feels when people don't respect the needs of people with disabilities, and how she doesn't want anyone's pity.

People with disabilities find themselves in a world that is not built or prepared for them. Debra writes that her disability does not define her. She tries to be more forceful in asking for help and in asking for the time and patience she needs to do things on her own. The world is not oriented toward accommodating those with disabilities.

In *Tempered Radicals*, she wrote about **psychological armoring**, a tactic that people use to defend themselves against threats to their identity and self-esteem. She says that we can armor ourselves by creating a separation between our self-worth and the world's treatment of us.

It often takes a while for stroke survivors to realize the need for psychological armoring. One study of stroke survivors found that if people treated them as inferior, they began to think of themselves differently, too. **Kathy Howard** was at a Sunday service one day, when an old friend came up to Kathy and her husband Jim. The lady asked Jim if Kathy was available to come to a meeting, but never once looked at or addressed Kathy. The following week, Kathy told the lady that she makes her own schedule.

Debra describes interactions between other stroke survivors and their friends, family, and community. There are common themes of fear about changes in the relationships and their loss of social standing. She writes that she wants

people to empathize with her situation, but not define her life as just the stroke and its consequences. The difference between legitimate sorrow for a person's situation and pity is that feeling sorry is about the situation, while pity is about the person. Debra writes that we can't control how people react to us, but we can control how we interact with them. Proactively taking control of a situation can help others react in kinder ways, and perhaps inspire change as well.

Chapter 12 Highlights: How the World Responds

1. Six years after her stroke, Debra went on a family trip to Peru. It had a four-day trek and a visit to Machu Picchu.

2. Debra's friends thought she was crazy. Debra still walked with a limp. She had no function of her right arm. She needed significant stretching and warm-ups for daily life. Her family knew that taking a trip like this would be emotionally significant for her.

3. Debra and Steve brought a saddle for the pack horses, so that Debra could ride whenever walking was too difficult. She found it invigorating to be active, relaxing to bond with family, and refreshing to be in such an isolated place.

4. In Machu Picchu, a group of people pushed by Debra while she was going down the stairs. It was hard for her to keep her safe position. She glared at and elbowed one of the people as they passed her.

5. On the next staircase, an older man reached out a helping hand. Debra glared at him too. She waved him away. She didn't need his help.

6. Debra gets angry when people don't respect the needs of people with disabilities. She doesn't like to be pitied. She doesn't like anyone to assume that she needs help, either.

7. People with disabilities, physical or speech or otherwise, find themselves in a world that is not built or prepared for them. Sometimes, they are not prepared for the reactions that they get in the world around them.

8. Debra says she tries to be more forceful in asking for help when she needs it. She also tries asking for the time or patience or other accommodations that she might need to do things by herself.

9. Nearly 20 percent of the American population live with a disability. That is over fifty million people.

10. Debra talks about ***psychological armoring***, a tactic that people use to defend themselves against threats to their identity and self-esteem. It can be applied to any situation in which a person's visible differences make them feel like they don't belong.

11. We can use psychological armoring to create a separation between our self-worth and the world's treatment of us. A study found that stroke survivors were vulnerable to how others treated them. If people treated them as inferior, then they began to think about themselves that way.

12. Debra writes about **Cindy Lopez**, a woman who had a stroke when she was 36 years old. She said that people her age immediately look at her and think, "What's wrong with you?" She struggled to adapt to how others would respond to her.

13. Cindy looked online but found few resources for young stroke survivors. She is getting the support of a counselor to help her adjust to living with ongoing physical or cognitive impairments.

14. Many people treat those with stroke symptoms as if they are mentally impaired. **Martina Varnado** uses a wheelchair due to her multiple sclerosis. She finds that even if she asks a question, people often respond to her husband instead of to her. She thinks people make assumptions when they see the wheelchair.

15. Martina's husband will sometimes look away so the person must look directly at her to answer. Other times, Martina will ask them to speak with her. She feels that the burden for communicating properly can't just fall on the person with the disability. Others need to learn how to be thoughtful and considerate.

16. When disabilities are less visible, other problems occur. **Ahaana Singh** recovered physically, but still has cognitive deficits. People treat her like nothing happened to her.

17. Sudden disability can impact your interactions with the public, but also with close friends. It is hard to lose close friends or social standing. How others treat you often has a huge impact on how your post stroke identity crisis and rediscovery of who you are.

18. Debra resented that one of her close friends felt pity for her. A family discussion led to this idea: Feeling sorry is about the situation, while feeling pity is about the person.

19. Debra wants people to empathize with her stroke and the challenges she faces but doesn't want to be identified by only her stroke and its consequences.

20. Taking control of a situation can help others react in a more positive way. **Trish Hambridge** lets people know she has a speech disorder as soon as she meets them. Trish finds that people are kinder and more willing to adapt when they are aware of her disability. Debra adopted this strategy and also finds it helpful with strangers.

21. We can't control how people react to us, but we can control how we interact with them.

Chapter 12 Points for Reflection: How the World Responds

1. Debra took her first big trip six years after her stroke. Have you or would **you feel confident traveling** abroad or **taking a big trip post-stroke**?

Not at all				Somewhat Confident					Very Confident
1	2	3	4	5	6	7	8	9	10

2. How often have **you experienced** someone **talking to your partner instead** of **you**?

Never	Few Times	Pretty Often	A Lot

3. Debra learned from Trish that telling someone right away that you have a speech problem seems to help the person understand and be nicer. Do **you agree** that this is a **helpful strategy**?

Disagree				Somewhat Agree					Strongly Agree
1	2	3	4	5	6	7	8	9	10

4. Debra struggled with sometimes **needing help**, but also **getting angry** if someone **offered help** if she didn't ask. Have **you experienced** these **feelings**?

Never	Few Times	Pretty Often	A Lot

5. "Psychological armoring" is a strategy to protect the reactions of others from hurting your feelings of self-worth. **Describe a time** when **someone reacted** to you in a way that **felt negative** because of your **stroke**? What **strategies help** you in these situations?

6. Debra and her family discussed "pity" as feeling bad for a person vs. feeling sorry for the situation. How **can you tell** if a friend is **feeling "pity"** for you or just **bad about the situation**?

7. Being proactive and educating others to better understand stroke and aphasia helps the stroke survivor to take control of the situation. **Share a time** when **you had to educate** a **friend** or a **stranger** about your **stroke**. What **lessons** have **you learned** about being **a stroke advocate**?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 13 Summary: Activities Adapted

Skiing has always been an important activity for Debra's family. She recounts the story of her family ski trip to Utah in 2005. Once Debra's family reaches the top of the slope, she is worried that it will be too challenging for her 10-year-old daughter Sarah. However, Sarah does not want to be left behind and successfully skis the slope. Debra reflects that she is now the one left behind on ski trips.

Our activities are an essential part of our identities. According to Debra, the activities we do are "one of the purest expressions of what we care about and how we define ourselves." For Debra, many of these activities are outdoorsy: skiing, sailing, biking, and more. She recalls how passionate and competitive she became about sailing at a young age. For many stroke survivors, these beloved activities are often out of reach. Losing the ability to continue these activities is painful. She revisits **Malik Thoma**, who shares that he was active and successful before his stroke. He continues to focus on what he has lost instead of looking forward.

Debra believes that it is important to try to understand the reasons why these activities are so important for us. By doing this, we can search for new ways to fill that need. Even though Debra can't run every day anymore, she has come to enjoy walking, swimming and tandem bike riding with her husband Steve. She even skis occasionally now, though she is careful not to risk injury. These activities allow Debra to hold on to her identity as an athlete.

Debra shares the story of **Anthony Santos**, a 19-year-old boy who had a stroke after a surgery. Before his stroke, Anthony's life revolved around sports. After his stroke, he used a wheelchair. However, he continues to make progress every day. Now he can walk independently and was able to enjoy touring Mexico on foot. He is relearning to wakeboard. Debra acknowledges that

adapting to new activities can feel inadequate. She would rather be able to take solo rides on her bike, but she celebrates that she can still participate in bike riding. While her activities look different now, their importance to her identity remain the same. Debra and her family plan to complete a cross-country bike ride to raise money and awareness for stroke prevention and rehabilitation.

Chapter 13 Highlights: Activities Adapted

1. Debra's family took a ski trip to Utah in 2005. Her kids were 10, 14, and 16 at the time. Debra worried that the slope was too challenging for her 10-year-old daughter Sarah. Sarah did not want to be left behind. She successfully skied the slope. Debra is now the one who gets left behind.

2. The activities we choose to do help to define ourselves. We cannot choose our family or friends, but we can choose our activities. Losing the ability to do these activities is very challenging.

3. Debra has sailed competitively from a young age. She was young, confident and did not like to be told that she could not do something.

4. People are happiest when they do activities that are stimulating and challenging. This might be music, sports or other physical activities. We build our lives around these activities. For many stroke survivors, these activities can be out of reach.

5. **Malik Thoma** shared that he used to be athletic and successful. He believes that his old self is gone. Malik unfortunately still looks back on what he has lost. He has not found a way to look forward.

6. **Intentional sensemaking** can help stroke survivors move past the initial trauma of stroke. We can think about why activities are so important to us. Then we can look for ways to fill that need. This can mean participating in new or modified activities.

7. Debra is a lifelong athlete. Debra used to jog daily. Now she gets exercise by walking, swimming, and tandem bike riding with her husband Steve. She enjoys being a sailing instructor to her children. These activities help Debra hold on to her identity as an athlete.

8. Debra introduces **Anthony Santos**. Anthony had a stroke after a surgery at the age of 19. Before his stroke, he was athletic. After his stroke, he had to use a wheelchair. He has made a lot of progress. He can walk independently, and he is learning how to wakeboard again. Anthony says he continued to make progress after the "12 month cutoff." His mother reflects that Anthony is much happier now that he can participate in sports again.

9. Debra acknowledges that adapting activities can feel inadequate. She enjoys tandem bike riding with Steve, but she still misses riding alone. However, she is grateful that she can still participate in bike riding. It remains a regular part of her life.

10. Debra recalls **Trish Hambridge**. Trish used to play softball and soccer. Now she plays golf. Her father made a special golf club for her. She misses softball and soccer, but she found new activities that bring her joy.

11. Debra considers how activities require trade-offs after stroke. Her physical therapist warned her against skiing. Debra uses a lot of caution to avoid injury. She believes that physical recovery is only part of the journey. Stroke survivors work to rebuild their entire lives. Some activities may be different now, but their importance is still the same. She has found new ways to enjoy being an athlete.

12. For Debra, it is important to acknowledge her identity as a stroke survivor. She works with the Pacific Stroke Association. This organization helps survivors thrive after a stroke. Debra can still do what she loves: making a difference in the world. She and her family plan to take a cross-country bike ride to raise money and awareness for stroke prevention and rehabilitation.

Chapter 13 Points for Reflection: Activities Adapted

1. Debra says 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." How **important** are your **activities** to your **identity**?

Not Important			Somewhat Important					Very Important	
1	2	3	4	5	6	7	8	9	10

2. Debra has many athletic hobbies. What are some of your **favorite activities**?

Movies/Television Art Reading Traveling

Nature Music

Cooking/Baking

Family

Games Collecting Sports

Crafting Other

3. How much have the **activities** you engage with **changed** since your stroke?

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

4. Debra acknowledges that **adapting** to **new activities** sometimes feels **inadequate**. Do you **feel this way**, too?

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

5. How have your changed activities **impacted your identity**?

6. Debra says, "Instead of mourning the loss of an activity forever, we can analyze the reasons why it is so important and search for new ways to fill that need." Are there **other activities** that might fill you with a **similar sense of fulfilment**?

7. What are some **new activities** that you have found after your stroke?

8. What is your biggest **take-away** from this chapter?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 14 Summary: Careers and Callings

Debra watches a YouTube video of herself giving a lecture recorded 5 years before her stroke. She views the version of Debra in that video as a "speaker, teacher, and creator of knowledge" who is assured of herself. She notes how much different that Debra is from the Debra she is today. In the months following her stroke, she would compare herself to the version of Debra that she saw in that video. With the loss of this part of her identity came a lot of grief. Her sense of self was so closely tied to her work. She realizes that her job as a Stanford professor had fulfilled every need on Maslow's pyramid: security, esteem and belonging, and fulfillment and actualization. Debra begins to try to identify what aspects of her work made it so important to her in the first place.

Work can fulfill different needs for everyone. The role that our jobs play in our lives is dynamic, just like our identities. With more younger people having strokes, and more people working past the age of 65, more stroke survivors are having their careers affected by their stroke. Debra writes about a young engineer named **Manny Gigante**. Before his stroke, his main goal was to work hard and make as much money as he could to be successful. After spending time in recovery, Manny began to reevaluate his priorities. He started focusing more on his future self and family rather than his past self, with the help of adopting the practice of focusing on "small wins." Manny found a deeper meaning in his new job and learned patience and understanding. By changing his approach to his job, he changed his life.

Debra tells us about **Malik Thoma**, CEO of a chain of day spas, is another stroke survivor who struggled to perform as he would have liked at his job post-stroke. He has not adopted the practice of focusing on small wins as Manny has. Debra proposes that it is important that stroke survivors determine *why* their jobs were so important to them and incorporate these values into their new identities in different ways. **Julia Fox Garrison**, another survivor, and former software company manager did this by becoming a writer and stroke advocate. She feels that she is still as successful as her pre-stroke self, only in new ways. Julia says, "My stroke became a gift to me."

Soon after Debra's stroke, she thought, "My world continues on, but without me in it!" After accepting that she had to give up her tenured position at Stanford, she could then focus on determining what about that job helped her to fulfill her core values in life. Post stroke, she fulfilled these parts of her identity by continuing to advise college students, reaching out to colleagues, and writing this book.

Chapter 14 Highlights: Careers and Callings

1. Debra sees a YouTube video of herself giving a lecture from 5-years before her stroke. She compares her current self to the version of herself in that video: a woman speaking with a clear, assured voice, full of authority. She saw a "speaker, teacher, and creator of knowledge."

2. Debra discusses the grief that came along with losing this part of her identity after her stroke. Her work as a professor and her sense of self were so interconnected. Now, she is challenged with determining *why* her work at Stanford was so valuable to her.

3. She begins to understand what it was about her job that was important to her about three years after her stroke. She realized that for her, being a professor had satisfied every need on Maslow's pyramid: security, esteem and belonging, and fulfillment and actualization.

4. Like identity, someone's relationship with work is a dynamic one, and unique for every person. Work can be a source of income, while also being "a critical source of esteem, accomplishment, and meaning."

5. With more younger people having strokes, and more people working past the age of 65, more stroke survivors are having their careers affected by their stroke. Many people associate their jobs with a large part of their identity.

6. Debra tells the story of **Manny Gigante**, a stroke survivor who was a young engineer when his stroke occurred. Before his stroke, he felt that the best way to be successful was to work hard and to make as much money as possible. Now, his definition of success has changed after he was forced to reevaluate his goals post-stroke.

7. Manny's new job as a loan officer allows him to help families in need, which he finds great value in. His new life allows him to better live out his true values. His stroke recovery journey has even inspired his oldest daughter to become an occupational therapist, and he is happy he can positively shape her life in this way.

8. **Malik Thoma**, another stroke survivor, and CEO of a chain of day spas, has not yet been as successful in finding ways to incorporate his core values into his new identity. Unlike Manny, he has not taken the approach of focusing on the "small wins" in his recovery process.

9. Debra talks about the research of Sally Maitlis, who studied professional musicians who had strokes. Although they were all musicians before their strokes, Sally noticed that they all took very different paths post-stroke. Their individual and unique "core values" led them to pursue things that would help them to fulfill the part of their identity that playing music used to fill.

10. Another stroke survivor, **Julia Fox Garrison**, was a manager at a software company. Her work was a very large part of her identity. She planned on returning to work as soon as possible.

11. Julia acknowledged that before her stroke, her motivation was success and fame. In contrast, her motivation to write her book post-stroke came from a desire to help others. She says, "My stroke became a gift to me. It allowed me to do things I never would have been able to do pre-stroke."

12. **Kathy Howard** became an advocate for stroke survivors after her stroke. She started a café for people with aphasia to help others change their attitudes toward their stroke.

13. A few months after Debra's stroke, the Dean at Stanford reached out to her about an event she was invited to attend. Debra was still at the beginning of her recovery, and wrote that it felt like, "My world continues on, but without me in it!"

14. After her stroke, and after giving up her position at Stanford, Debra was forced to determine what really mattered to her in life. Now that the stress of work was not in her life, she could focus on what was important to her.

15. Upon reflecting on *why* being a professor was so important to her, she found new ways to incorporate these core values and meaning into her post-stroke identity. One thing she valued, creating and sharing knowledge, was her motivation to write this book.

Chapter 14 Points for Reflection: Careers and Callings

1. Debra opens the chapter by talking about how she used to **compare** her post-stroke identity to her pre-stroke self. How often do you find yourself **comparing** who you are now **to your pre-stroke identity?**

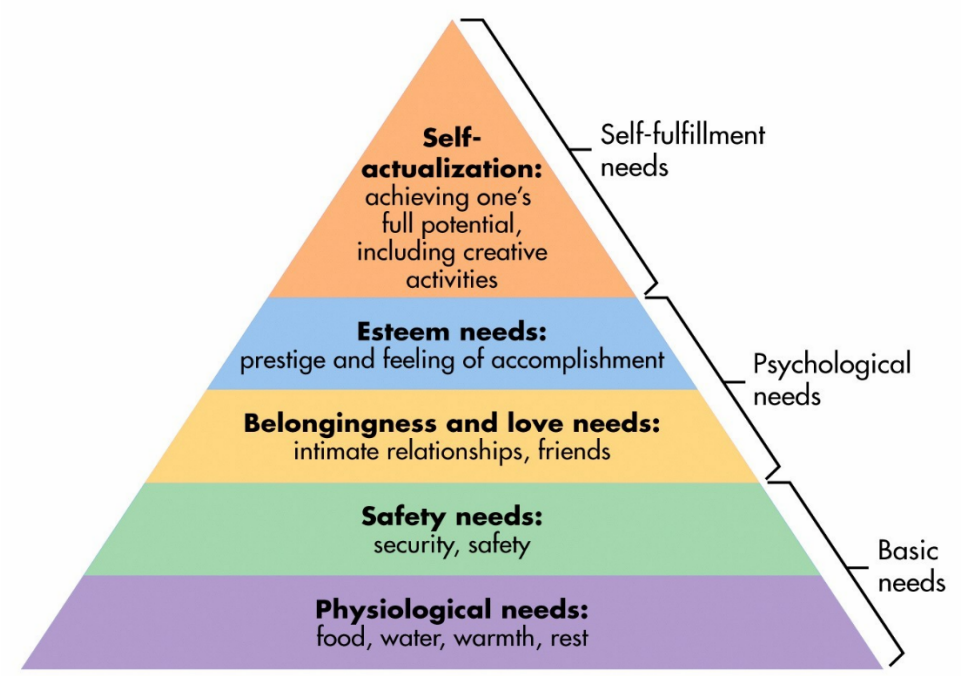
Never Sometimes Often

2. Debra realizes that her previous job as a professor fulfilled the highest levels of **Maslow's hierarchy of needs** for her. What **needs** of yours did your previous job **fulfill?**

Physiological Safety/Security Belonging

Fulfillment/Actualization

Esteem None



3. This chapter discusses how someone's **relationship with their work** is a dynamic one, unique to every person. After your stroke, how important was it to you that you (at some point) **returned to work?**

Not Important				Somewhat Important					Very Important
1	2	3	4	5	6	7	8	9	10

4. Debra discusses how her stroke forced her to determine her **core values**, and how she can incorporate those core values and meaning into her new post-stroke identity. What are **some values** that you consider to be at **the core of your identity?**

5. After his stroke, Manny Gigante redefined what **success** (both in his career and in his life) meant to him. What does **"success" mean** to you?

6. Debra discusses how, after determining her **core values**, she found ways to incorporate these values into her new identity. For example, because she values sharing and creating knowledge, she decided to write this book. In what ways have you (or could you) **incorporate** one of your **values** into your life today?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 15 Summary: Dealing with Financial Strain

Debra introduces **Cam Compton**, a 52 year-old stroke survivor who was caring for her 16 year old daughter and 10 year old granddaughter by herself. Before her stroke, Cam's financial situation was comfortable. However, after her stroke, Cam has only regained 60% of her pre-stroke income. That income loss on top of the $20,000 hospital bill was really tough for her in the beginning.

Strokes usually hit financially in two ways. The first way is that it can directly cost survivors and their families a lot of money. A 2014 pamphlet from the American Stroke Association estimates that the lifetime cost of an ischemic stroke is $140,048. The second way is that many survivors lose their wages, which often ends up being a more significant challenge than the direct medical costs.

After her husband **Randy**'s stroke, Rose Miller left her job so she could support Randy, who was unable to return to work. Randy receives 60% of his prior salary because of his disability insurance, but Randy and Rose still make less than half of what they did before. Even with good medical insurance, their share of the medical bills for deductibles and co-payments depleted their savings. The therapy that was covered by insurance was limited, too, so they paid out of pocket for more.

Debra writes that almost every stroke survivor has stories about the financial pressures post-stroke. As the income and wealth gap in our country grows, the disparity gets worse as well. The racial wealth gap grows, too. The median household wealth for a white family is thirteen times the median for Black families. Unless these trends can be reversed, the financial impact of a stroke or any major health crisis will continue to impact lower-income families and families of color more than others. Debra says that she is luckier than others. She has been able to focus on seeking great medical care rather than basic needs. Everyone struggles with different aspects of their recovery, and finances play a role in defining that experience, just like any other aspect of the situation.

Chapter 15 Highlights: Dealing with Financial Strain

1. When she had her stroke, **Cam Compton** was single, fifty-two, and caring for her daughter and granddaughter. Before her stroke, she had a steady job with benefits and was able to raise two kids and live comfortably.

2. Post-stroke, Cam was unable to work for 6 months. She eased back into work after that and eventually began to work 24 hours a week and received benefits again. That was the only amount of work that she could handle.

3. Cam had good health insurance, but her share of the main hospital bill was still around $20,000. Her lost income had an even bigger impact. She has never regained more than 60% of her pre-stroke income.

4. Family and friends helped out a little and Cam cut back expenses as best as she could. She had to get more creative and learn to ask for help. She found out that the hospital could write off part of the bill if you really have financial hardship. She ended up paying about half of it.

5. Cam tried to always keep looking forward and make the best of her situation. She gets mad and stressed sometimes. In those times, she says she goes to sleep and by morning has already forgotten about it.

6. Like Cam's situation, most strokes have **2 main financial impacts**: the direct cost from inpatient services, rehab, and follow-up care, and the loss of wages. The lost wages typically are more significant to survivors and their families.

7. In 2014, the American Stroke Association estimated that the lifetime cost of an ischemic stroke is $140,048. The median family net worth in the United States is $45,000. That lifetime cost amounts to more than three times the average family's total net worth.

8. For many people, most of the costs will be covered by insurance, but 8.8% of Americans still don't have health insurance. And even with insurance covering most of the costs, there are still many fees that aren't covered, such as deductibles, co-pays, and other services.

9. **Randy Miller** and his wife Rose faced difficulties with their loss of income. Rose quit her job so she could become a full-time caregiver for Randy, who was unable to return to work. Randy receives 60% of his prior salary due to disability insurance, but they still make less than half of what they did before.

10. Even with good medical insurance, they quickly depleted their savings due to all of the costs. Randy's insurance covered some therapy three years after his stroke, but it was limited, so they had to pay out of pocket for more.

11. College loans for their children were another heavy burden on their finances. Luckily, they learned that with Randy's disability, they could apply for relief from the significant student loans.

12. The loans were in holding and payments were suspended, but even so, if the loans were discharged, Randy and Rose would still have to declare the forgiven amount as income and pay taxes on it.

13. Almost every stroke survivor Debra has met has similar stories about how their life has changed because of financial pressure. **Trish Hambridge** left her home and friends in California so she could live less expensively in Florida. **Michael McDermott** had to reduce his spending so that he could live on social security after he lost his job.

14. Debra writes that both situations are challenging, and that the group of survivors she interviewed is on average more financially stable than most. Many survivors struggle to put food on the table, and those who struggled financially before their stroke face even greater difficulties than before.

15. As the income and wealth gap in our country grows, the disparity gets worse. Real wages have grown by 33% for the top group, less than 10% for the people in the middle, and have actually fallen for the bottom 10%.

16. The racial wealth gap is growing, too. The median household wealth for a white family is more than 13 times that of the median for Black families.

17. Unless these trends can be reversed, the financial impact of a stroke or any major health crisis will continue to impact lower-income families and families of color greater than others.

18. Those with greater financial burdens are not able to focus on seeking great medical care. They must focus on their basic needs first.

Chapter 15 Points for Reflection: Dealing with Financial Strain

1. Debra said that strokes usually hit financially in two ways: with the **direct costs** of the **medical bills** and with the **loss of wages**. Do you find this to be true in your experience?

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

2. A sports program waived its normal fees until Cam got her financial situation more stable. How much **financial stress** have you felt due to your stroke?

None				A Little					A Lot
1	2	3	4	5	6	7	8	9	10

3. Randy and his wife found that their new financial situation challenged the aspect of their old identity that related to what it meant to be a good parent. Have you had a **change** in your **identity** because of your **finances**?

None				A Little					A Lot
1	2	3	4	5	6	7	8	9	10

4. Debra said that almost every stroke survivor she has met had stories about how life has changed because of financial pressure. Do you agree that most survivors have had to **change their lives** because of their **finances**?

Disagree				Somewhat Agree					Strongly Agree
1	2	3	4	5	6	7	8	9	10

5. Cam works to keep a positive, problem-solving attitude when it comes to her finances. She said that when she's feeling stressed, she has to sleep. What are some **strategies** you use to cope with stress?

6. Cam said that she had to get creative and learn that there are ways to get help if you ask for it. What are some ways in which you have had to be **creative** to **get help**?

7. Trish and Michael both made big changes to their life because of financial pressure. Describe the types of **changes** you have made because of **finances**.

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

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

Debra begins the chapter by describing her first stay in the ICU at Stanford Hospital. It was difficult for her to communicate anything at this point. The nurse was talking to her in a voice adults typically use to speak to infants. Her husband Steve realized that she was extremely irritated by this and asked for a different nurse to be assigned to her room. This experience was a lesson that it is important to voice their concerns and questions about Debra's medical care.

The American medical system is not set up well for individual care. However, if you voice your concerns, most medical professionals are happy to help. Debra shares the story of **Jim Indelicato**, a stroke survivor whose family advocates for his care constantly. Their constant support has led to doctors treating Jim better and trying new treatments that ended up benefiting him in his recovery.

Debra shares the challenges that she and many other stroke survivors have had with getting adequate healthcare coverage. Insurance companies tend to treat stroke rehab as if it is an acute illness, rather than a life-long recovery process. Because of this, many survivors don't receive the coverage they need to recover as much as they can. Stroke survivor **Cam Compton** was incorrectly told by her insurance provider that she could go back to work full time, and therefore would lose her disability benefits. She went without benefits for 9 months until a lawyer she hired helped her get them back. She had to pay him a 20% fee which she didn't realize applied to future disability payments as well. After asking her lawyer if he could waive the additional payments, he did. Cam and Debra have both learned through their recovery journey that "you don't get what you don't ask for."

Debra and the other stroke survivors in this chapter learned that advocacy is essential in order to receive the care and coverage they require. Most insurance companies limit the number of therapy sessions you can receive.

This can severely limit a survivor's potential to improve during their recovery. Having to navigate the healthcare system and coverage from insurance companies adds another layer of stress to the already stressful situation that stroke survivors and their families find themselves in. Debra and others have learned that sustained self-advocacy, by a stroke survivor and those who support them, is critical to receiving adequate medical care and insurance coverage.

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

1. Debra describes the nurse assigned to her room in her first ICU stay at Stanford Hospital, saying that she spoke to Debra in a condescending voice that adults often use to speak to infants. Her husband Steve could tell that this irritated her and that it did not help her anxiety.

2. Steve contacted the nursing supervisor, and they changed the nurse assigned to her room. This was a lesson. Debra and her supporters would have to advocate in order for her to receive the care she needed during her recovery.

3. Debra quotes the work of Kathy Charmaz, a professor in sociology who discusses the issue of the healthcare system treating patients with chronic illnesses within a "framework of care designed for those with acute illnesses, however inappropriate that framework is."

4. **Jim Indelicato**, another stroke survivor who is a U.S. Air Force and National Guard veteran, is introduced. His family has been advocating for him in medical settings for years. His daughter even convinced his doctor to try a new course of treatment that eventually allowed him to stop using his ventilator four and a half years post-stroke.

5. Jim's wife, Diane, brought in pictures of him taken before his stroke in the hopes that it would encourage the medical staff to see him (and therefore treat him) differently. Jim says that if it weren't for his family constantly advocating for him, "he wouldn't be where he is today."

6. Debra and Steve received a medical bill from their insurance company after her stent surgery. The cost of her hospital stay totaled $990,000. They were in disbelief that patients could be expected to pay that much.

7. As the process of handling hospital bills and fighting with insurance became more time consuming, it became difficult for Steve to devote the time he needed to Debra and their children.

8. A close friend suggested that Steve have someone else handle the financial management part of things. Hiring an affordable health-care financial manager allowed him to focus more on supporting Debra and the family during the recovery process.

9. **Cam Compton** is a stroke survivor who has had her share of difficulties with lack of insurance coverage. Cam's insurance company insisted that she could go back to work full-time and discontinued her disability benefits for 9 months. After hiring a lawyer, she was able to get that money back. The agreement she signed with her lawyer entitled him to a 20% fee as well as 20% of her disability payments for three years. After asking him if he could stop taking a percentage of her income, he agreed. This taught her that "you don't get what you don't ask for."

10. Debra shares the frustrating experience had by stroke survivor **Mark Wells**, a fifty-three-year-old African American accountant in St. Louis, who was told that he would have to be on disability for two whole years before his Medicare coverage would kick in.

11. Stroke survivors **Manny Gigante** and **Kathy Howard** express how unaffordable therapy services are for people recovering from stroke. Both have had to choose to go without therapy due to the cost.

12. Both Debra and stroke survivor **Anthony Santos** share their experiences fighting for coverage of therapies that insurance companies claim are not "medically necessary," and succeeding.

13. Debra points out that while all the survivors included in this book have had insurance coverage at the time of their stroke, this is not always the case.

14. Insurance companies typically limit the number of therapy sessions someone can have in a week. Doctors and therapists think more therapy can improve recovery outcomes.

15. Having to navigate the healthcare system and coverage from insurance companies adds another layer of stress to the already stressful situation that stroke survivors and their families find themselves in.

16. Debra and her support system have learned that they must "take ownership of her care" by advocating for her and fighting for the coverage that she needs.

Chapter 16 Points for Reflection: Advocating in the U.S. Medical System

1. Debra describes a frustrating situation she had with a nurse during one of her hospital stays after her stroke. How satisfied were you with the **quality of care** you received after your stroke?

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

2. Debra recalls situations in which her husband, Steve, has had to advocate for adequate medical care and insurance coverage. Have you or anyone in your life had to **advocate** for care or coverage during your recovery journey?

Self

Parent

Child

Friend

Spouse

No One

Other Family Member

3. Many stroke survivors experience challenges when it comes to navigating their healthcare and insurance coverage. **What aspects**, if any, of your **healthcare** have you found **challenging** since your stroke?

Receiving Therapy

Mental Health Support

Insurance Coverage

Unanswered Questions

Something Else:

4. Debra and others frequently describe struggling to receive adequate insurance coverage post-stroke as a "fight." How often have you felt that you or those who support you have had to "**fight**" for you to receive the coverage you need?

Never Sometimes Often Constantly

5. Debra and other survivors she interviewed discuss moments when they have advocated for the help or care that they need, and their needs were then met by medical professionals or insurance providers. **Have you had moments when you had to advocate for yourself?** Did you feel it was successful?

6. A common obstacle to proper care for stroke survivors is receiving adequate insurance coverage. Have you experienced **any difficulties with the coverage your insurance is providing** for medical expenses for stroke recovery services?

7. Debra has learned that most medical staff she encounters are "highly receptive" to her requests and questions and are "eager to improve care." What **positive experiences** (if any) have you had with medical professionals during your stroke recovery journey?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 17 Summary: Reclaiming the Basics

Debra says that her recovery was not about getting back to exactly who she was before her stroke. She says that it was more about reclaiming the pieces that mattered most to her identity. For many stroke survivors, that means rebuilding a sense of self-confidence, independence, and stability. This lays the foundation for creating a rewarding life.

Many people feel broken after their stroke. The uncertain path of recovery can add to the stress of rehab and feel overwhelming for survivors. However, remastering the basics provides a scaffold for future success. Appreciating all the small wins that add up can benefit both mental health and physical rehab. For **Randy Miller**, his wife Rose explains that the three years after Randy's stroke were like "Watching pieces fall into place. There were blank spaces, then all of a sudden, a piece would drop in." These survivors chose to look at the functions that have been regained rather than the functions that have been lost.

Another challenge of recovery is understanding how the new physical deficits redefine a person's identity. Professor Kaufman writes how the mind, body, and self are often inseparable, so it can be hard to feel whole without having full physical functions. For **Julia Fox Garrison**, her loss of physical capabilities made her feel like she lost her independence and sense of self. Finding a balance for independence can be challenging for both survivors and their supporters. That is why Debra says survivors can build up small steps towards independent functions. She says, "the small steps add up."

Sometimes, survivors may need to struggle through a task so that they can be one step closer to achieving their next goal. Even though this can be hard for supporters who want to help, it is a necessary part of the recovery process and regaining independence. In Debra's interviews, she found that most survivors

felt like a burden to others. But Debra also found that most family members embrace their new role and want to support their loved one. Additionally, leaning into your support system can deepen your relationships, and everyone can be pushed to grow in new ways.

Debra recalls regaining her independence when swimming, small win by small win. She no longer fears not meeting her basic needs, and she has adapted in new ways to regain her capabilities. As a result, she can now focus on goals beyond the basics.

Chapter 17 Highlights: Reclaiming the Basics

1. In 2010, Debra's son Danny watched his mother say her first words post-stroke: "My name is Debra Meyerson." This sentence, plus her next phrase, "I love you Steve!" were major breakthroughs in her speech and language recovery.

2. Debra discusses how after her stroke, she had to fight to regain even the most basic needs on Maslow's hierarchy. Although those first words were basic and she required support to say them, they were foundational to her recovery.

3. Debra writes that recovery is not about getting back to exactly who we were but it's about reclaiming the pieces that mean the most to us.

4. Deciding what matters most in the recovery journey helps to establish recovery goals. For many people, these goals include building more self-confidence, independence, or stability.

5. Debra felt broken after her stroke. Others felt helpless, exhausted, and misunderstood. Dealing with a loss of function can be difficult to manage, both for the survivor and their supporters.

6. Loss of physical function can be devastating, and it can be even harder not knowing the trajectory of recovery after a stroke.

7. Focusing on small wins can help survivors feel less overwhelmed with recovery and strengthen their foundational skills. This can have benefits for both mental health and physical rehab.

8. Looking at the progress that has been regained rather than the function that has been lost is a positive perspective that can help someone keep looking ahead towards continued growth.

9. Debra writes that progress and motivation build on each other and shares the observation of **Anthony Santos**'s mother, Martina: "Now that he's starting to see results, he's not sad anymore; he doesn't get as frustrated anymore. Even though he would like it to be quicker!"

10. Debra writes that many stroke survivors struggle with questions about how their physical impairments redefine them. Professor Kaufman notes how the mind, body, and self are inextricably linked for many Americans, making the loss of physical capabilities a significant threat to one's sense of self.

11. Many survivors, including **Julia Fox Garrison**, feel guilty for relying on others. The loss of independence can result in feelings of anger, humiliation, and failure which can be a balancing act for survivors and their supporters.

12. Debra saw that people did not know how much they should help her when she struggled. Some waited to see if she could do a task herself or asked for help, while others felt compelled to jump in and help.

13. Julia Fox Garrison tells her husband how she needs to accomplish tasks by herself to increase her independence. As a part of recovery, Julia needed to push herself to accomplish a small victory so she could reach for the next achievable goal.

14. Often, survivors feel like a burden to their supporters, resulting in feelings of shame and guilt. However, carepartners may be happy to take on some of the responsibility so that their loved one can focus on recovery.

15. Carepartners can also renegotiate parts of their identities in the context of supportive communities, like in stroke support groups.

16. Debra recalls returning home from swimming, and her son Danny was surprised that she did so independently. It took her seven years to regain her independence, but she adapted to the challenges and has found a way to achieve that goal, in part by being willing to ask for help when she needs it.

17. Debra is at a point in her recovery where she can move up on Maslow's hierarchy of needs and begin to build her sense of belonging, purpose, and fulfillment in this "new normal."

Chapter 17 Points for Reflection: Reclaiming the Basics

1. Debra says that her recovery was not about getting back to exactly who she was before her stroke. How much do you agree with the idea that **recovery is more about reclaiming the pieces that matter most**?

Disagree				Somewhat Agree				Strongly Agree	
1	2	3	4	5	6	7	8	9	10

2. Debra says that some survivors choose to **look at the functions that have been regained rather than the functions that have been lost**. How often do you look at the functions you have regained?

Not at all	Occasionally	Frequently

3. Sometimes it can be hard to balance acceptance of post stroke changes with the **determination** to push to recover as much as possible. Has this been **difficult** for you?

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

4. Julia Fox Garrison mentions how she needs to **push herself** to accomplish new goals and regain her independence. How challenging has it been for you to push yourself?

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

5. After 7 years, Debra independently went swimming again. She had to **make many adaptations** for that to be possible. In what ways have you adapted your way of doing things to regain independence in something important to you?

6. Debra said that she is now at a point where she can work on meeting more than just her basic needs. **What is a goal that you have beyond your basic needs**? What **small wins** do you still need to accomplish to **reach that goal**?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 18 Summary: Choice in Our New Identities

Debra begins the chapter by saying there are **3 choices for survivors**: to try and recover your old life, to accept your stroke passively, or to embrace the stroke and include it in the new path that you create for your life. While having a stroke can limit options, it also presents stroke survivors with the opportunity to prioritize what matters and to decide who they want to become. **Julia Fox Garrison** celebrates her 20 year "stroke anniversary." She is proud of her progress and has adapted to her significant life changes.

Because relationships evolve after a stroke, survivors can determine what they want out of their relationships and who they want to surround themselves with. While some relationships may drift, other relationships may be strengthened. Debra has adapted the ways she socializes with her closest friends, but she values these relationships now more than ever. Feeling a sense of community can help survivors understand their own identities better.

Once stroke survivors are beyond the initial stages of recovery, continuing to set goals is an important part of ongoing recovery and personal growth. To get stronger and healthier, survivors can work to achieve goals that are *specific, realizable,* and *immediate*. Setting goals with this framework in mind helps with motivation and preventing burnout. For **Sean Maloney**, he uses his stroke advocacy to target communication goals, where he uses scripts as a support when giving speeches. For survivors of recent strokes, it can be challenging to prioritize certain goals and remain positive. Some may get stuck grieving the loss of who they were. However, looking at recovery as a "path to knowledge and self-discovery" can make the journey easier.

Jim Indelicato used his determination to focus on what mattered most in his life and positively impact the lives of others. He turned to his family values and allowed these to shape his post-stroke life. Stroke recovery can cause survivors to live a more rewarding life overall. Debra has learned new ways to realize her passions, and she is grateful for the love and support that she has received.

Debra notes that because our lives are constantly changing, our identities are also changing all the time, regardless of traumas like stroke. Therefore, all survivors are partly the same and partly different from who they were pre-stroke. After her stroke, Debra has become more aware of what gives her a sense of purpose. Therefore, she has been able to challenge herself to achieve and expand her potential for growth.

Chapter 18 Highlights: Choice in Our New Identities

1. Debra starts by saying that a stroke does not seal a person's fate. Stroke survivors still have choices with how they will move forward. Survivors can try to recover their old life, passively accept the stroke, or embrace the stroke moving forward in recovery.

2. A stroke disrupts the trajectory that a person originally had for their life, although Debra says that *opportunity* can also result from stroke. These include the chance to focus on what is most important to you, reevaluate what matters and why, and the chance to decide who you want to become.

3. **Julia Fox Garrison** mentions how she celebrates her stroke anniversary because it reminds her that she won. She has gotten to embrace her roles (wife, mother, daughter, sister, friend) for another 20 years, which she is grateful for.

4. **José Cofiño**, a friend of Debra's husband, lived with ALS and decided to regain control by choosing what he wanted the rest of his life to look like. He founded an organization to raise money and connect people living with ALS.

5. Relationships inevitably change after a stroke, so survivors can determine who they want in their lives and what they want out of their relationships.

6. A strong sense of community can help survivors understand their own identities better, and different people will find community in different ways.

7. Continuing to set goals helps survivors prioritize what matters most and appreciate the small wins that add up. Goals should be *specific, realizable,* and *immediate*.

8. **Sean Maloney** approaches his stroke advocacy with small, specific goals in mind. To improve his speeches, he uses scripts for support. This is helping him build independence in his communication.

9. It can be difficult for recent survivors to prioritize certain goals and adopt these positive outlooks. But the early challenges can become a "path to knowledge and self-discovery," says Professor Kathy Charmaz.

10. **Jim Indelicato** used his determination during stroke recovery to turn inward and prioritize his family and helping others. Survivors can ultimately build more rewarding lives after their strokes.

11. Debra has found new ways to honor her core values, whether it be by supporting colleagues who push gender issues, coaching her children during family sailing trips, finding alternative ways to exercise, or always seeking new challenges.

12. Debra mentions how our lives are always evolving, which means that our identities are dynamic and changing over time, regardless of traumas. Therefore, survivors are partly the same and partly different from who they were pre-stroke.

13. Debra is more in tune with what gives her meaning, and she has shaped her new life and choices around that to prioritize what matters most.

14. Through writing this book with her son Danny, Debra has learned to obsess less over her deficiencies and basic needs so that she can instead focus on building a more fulfilling life full of growth.

Chapter 18 Points for Reflection: Choice in Our New Identities

1. How much have you **embraced** your new life post-stroke?

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

2. Have any **new opportunities** resulted for you after your stroke that have surprised you?

None A Few Many

3. What did you think about Julia Fox Garrison **celebrating** her "stroke anniversary"?

4. Debra's stroke has allowed her to value her friendships and relationships more than ever. Jim Indelicato now prioritizes time with his family. How have your **priorities changed** after your stroke?

5. What is something **new** that you have learned about yourself since your stroke?

6. What **goals** are most important to you in the next 6 months?

7. What were some key takeaways for you after reading this chapter?

Identity Theft: Rediscovering Ourselves After Stroke

By Debra E. Meyerson, PhD with Danny Zuckerman

Chapter 19 Summary: Fulfillment Through Growth

Debra stayed with a friend and colleague, Robin Ely, for four months in Boston. Robin noted a change in Debra's personal outlook. Robin described Debra as being "high strung" and a "glass half-empty" type of person when she was working. Now, Debra was the happiest Robin had ever seen her. Debra thinks her change was due in part to feeling encouraged by the therapy trial and by regaining some independence by living in Boston.

Debra also credits the change in her daily outlook to personal growth. She said for most of her life, her approach to the world was "determination and stubborn ambition." Her struggle to recover from the stroke made her slow down, think about her future, and figure out how to adjust to her changing goals. She began to appreciate what she has in her life more. She focused more on ways to become happier and more fulfilled.

Debra adopted recognizing silver linings and opportunities for growth as her main strategies. This approach made facing adversity more tolerable and meaningful. Holocaust survivor, Victor Frankel, highlights the critical importance of having meaning in your life. Debra shares that stroke allows for opportunities of both challenge and growth. If you only focus on what it means to be 100% recovered, it can feel overwhelming. Debra recommends clarifying values, setting goals, and celebrating small wins as you pursue them.

The stroke stole Debra's main identity as a professor. She felt her sense of self-worth and purpose were gone. She hoped that writing the book would restore that role and show everyone they were wrong. But it did not play out that way. Instead, in the process of listening to the many stroke survivors she interviewed, Debra learned to reflect, listen, and think about what was most important to share about recovery. Debra says the stroke knocked her down, but she got back up. She says, "I am still Debra Meyerson, but not the same

Debra Meyerson."

Debra credits her recovery to all she has learned from the other stroke survivors and to the support of her family and friends. She offers that **survivors who are thriving share common attributes**:

- A viewpoint that **recovery goes beyond 12 months**;
- A **focus on the future** vs. recovering the past;
- **Accepting support**;
- Setting **achievable goals**;
- **Celebrating small wins** and **silver linings**;
- Drawing on **deeper meaning**; and
- **Recognizing** moments of **personal growth**.

Debra concludes that a stroke may limit some of our options, but it "does not have to steal our future or who we get to become next."

Chapter 19 Highlights: Fulfillment Through Growth

1. Debra went to Boston for four months for a clinical trial of Melodic Intonation Therapy. She stayed with an old friend and colleague, Robin Ely. Robin noticed Debra was no longer "high strung" or had a "glass half-empty" outlook. Instead, she is the happiest that Robin has ever seen her.

2. There were several reasons for the change. Debra was encouraged by the therapy. She felt happy to reclaim some independence by living in Boston on her own. But she also thinks it had to do with her experience of personal growth.

3. Her outlook had changed. She was happier and more positive. Pre-stroke, her approach to the world had always been "determination and stubborn ambition."

4. Fighting for recovery from her stroke forced Debra to slow down and reflect in new ways. To think about her future, Debra had to let go of some ways of being that didn't fit her changing goals.

5. Debra realized that her pre-stroke perspective on life was narrow and very work focused. She started to appreciate all the other aspects of her life more. She focused on ways to become happier and more fulfilled.

6. Debra adopted recognizing silver linings and opportunities for growth as her main strategies. This approach made facing adversity more tolerable and meaningful.

7. Debra explains the idea of "flow"— a state where you are absorbed by the activity. You feel challenged, but the effort is rewarding. She also talks about meaning. Holocaust survivor, Victor Frankel, highlights the critical importance of having meaning in your life.

8. Stroke allows for opportunities of both challenge and growth. If survivors only focus on what it means to be 100% recovered, it can feel overwhelming. Clarifying values, setting goals, and celebrating small wins as you pursue them are important. This helps you to "achieve not just recovery but satisfying growth and fundamental meaning in our lives."

9. The stroke stole Debra's main identity as an educator. She felt her sense of self-worth and purpose were gone. She hoped that writing the book with her son Danny would restore that role and show everyone they were wrong. But it "didn't play out that way."

10. Debra was inspired and learned lessons from the stroke survivors she interviewed. She learned to think about what was most important to share about recovery.

11. It has not been an easy process. Debra is grateful for her support network. She has learned more fully who she is. She has gotten better at setting small goals. She can better recognize when she has fallen into a funk and adjust her outlook. She has learned to better feel and express gratitude, consideration, and vulnerability.

12. Debra says the stroke knocked her down, but she got back up. She states, "I am still Debra Meyerson, but not the same Debra Meyerson."

13. The support of her family and friends has helped her through her struggles and challenges. Her research for the book helped her to make sense of what she was learning. She says, "I am *Debra Meyerson* because of those around me."

14. Debra offers that stroke **survivors who are thriving share common attributes**:

- A viewpoint that **recovery goes beyond 12 months**;
- A **focus on the future** vs. recovering the past;
- **Accepting support**;
- Setting **achievable goals**;
- **Celebrating small wins** and **silver linings**;
- Drawing on **deeper meaning**; and
- **Recognizing** moments of **personal growth**.

15. Debra shared that it is important to notice and be aware of the moments that count and make a difference. The slower pace of her post-stroke life makes it easier to notice, pause and think about them. These moments add up and can be a source of light. Soon there is a "pathway lit with our own values, leading to a life that will be meaningful and fulfilling."

16. Debra concludes that a stroke may limit some of our options, but it "does not have to steal our future or who we get to become next."

Chapter 19 Points for Reflection: Fulfillment Through Growth

1. **Before** your stroke, were you more a **glass half-full** or **glass half-empty** person?

More Half-Full Split Both Ways More Half-Empty

It Depends Other

2. **After** your stroke, are you more **a glass half-full** or **glass half-empty** person?

More Half-Full Split Both Ways More Half-Empty

It Depends Other

3. This book promotes **small wins** and **silver linings** as important strategies for **personal growth**. Has it influenced the way you are thinking about **your goals** and **sense of hope**?

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

4. Debra lists **approaches to recovery** that help a stroke survivor **thrive**. Which ones are **strengths for you**?
    a. View that recovery goes past 12 months
    b. Focus on future vs. recovering the past
    c. Drawing on deeper meaning and values
    d. Accepting support
    e. Recognizing growth
    f. Setting achievable goals
    g. Celebrating silver linings or small wins
    h. Other

5. How has this book helped you to think about **rebuilding** a **positive post-stroke identity**? What are your most important take-aways?

6. What **three words** would you use to describe yourself before your stroke? After your stroke? How do you hope to describe yourself in the future?

7. Debra concludes by saying, a stroke may limit some of our options, but it "*does not have to steal our future or who we get to become next*." What does this **mean to you?**