

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



Rebuilding Identity and Rewarding Lives

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
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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?**