

Identity Theft: Rediscovering Ourselves After Stroke

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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.

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**?