

## ***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.



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?