

Identity Theft: Rediscovering Ourselves After Stroke

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

1. Debra writes that as her “condition improved, I had to be my own advocate.” (p. 183)
 - a. Were there any examples of stroke survivors and their families advocating for themselves that you found inspiring in the book?
 - i. Which ones and why?
 - b. What was your experience navigating the medical system in the aftermath of your survivor’s stroke?
 - i. Did it change as you became more experienced advocating for your survivor, or as you moved from the acute medical environment to rehab and other care settings?
 - c. Have you had success in advocating for your survivor as well as for your own needs?
 - i. If so, share some examples that make you proud.
 - d. What have been your biggest barriers or hurdles as an advocate?
 - e. What advice would you give to survivors and carepartners who are still early in recovery?

2. Consider Jim Indelicato. After his stroke, his wife Diane recounted how “it often felt...as if nobody was looking past his immediate survival.” (p. 185)
 - a. Why does Diane’s daughter suggest bringing a photo of “how Daddy was” into the hospital?
 - i. What is the impact of sharing this photo with the hospital staff?
 - b. Do you utilize any meaningful objects or symbols from pre-stroke life?
 - i. What impact do these items have on you and how do they make you feel?
 - c. Does your survivor utilize any meaningful objects or symbols of their

pre-stroke life and identity?

- i.** What impact have these items had on their recovery?
- d.** Do these items have an impact on you and how you care for your survivor?
 - i.** Has the impact changed over time?
- e.** Does your survivor avoid any objects or symbols of their pre-stroke life and identity?
 - i.** Does this have an impact on you and how you care for your survivor?