



Rebuilding Identity and Rewarding Lives

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

Chapter 21: Building a Movement to Catalyze Change in the Stroke System of Care

1. "We founded Stroke Onward in 2019 based on our belief that 'an identity lens' could help many stroke survivors, and that we could bring that perspective to other survivors and families in a way that could help."
 - a. How do you think an "identity lens" can be applied to support stroke survivors and their families?
 - b. Have you seen this approach make a difference in your own experience or that of others?
 - c. In what ways can organizations like Stroke Onward contribute to improving support for stroke survivors?
 - d. What role do you think raising awareness about the emotional journey of stroke recovery plays in creating change?

2. "Much of Stroke Onward's work thus far has focused on raising awareness about this problem. That includes speaking widely at conferences and other gatherings, and developing material available for free on the Stroke Onward website."
 - a. How have you become aware of resources and support for stroke survivors and carepartners?
 - b. Have you found any particularly helpful or informative sources?
 - c. In what ways can organizations effectively raise awareness and promote change in the stroke care system?
 - d. What are some potential challenges or barriers to disseminating information about stroke recovery and support?



Rebuilding Identity and Rewarding Lives

3. "Education isn't enough – rigorous research must validate the value of new care methods if they are to become the standard of care."
 - a. How important do you think research is in driving change in the stroke care system?
 - b. Have you been involved in or aware of any research studies related to stroke recovery?
 - c. What role do you think organizations like Stroke Onward can play in promoting and supporting relevant research?

4. "For real change to happen, building robust and diverse communities of people concerned with this issue isn't enough. These communities have to be mobilized to do the work necessary to overcome the very substantial obstacles to change, and then actively drive for change."
 - a. How can communities of stroke survivors, carepartners, and healthcare professionals be effectively mobilized to drive change?
 - b. Have you been part of or witnessed any successful mobilization efforts?
 - c. What are some potential strategies for overcoming obstacles to change in the stroke care system?
 - d. In what ways can collaboration and partnership among different stakeholders contribute to meaningful change?

5. "We have barely begun to understand the complexities of the US medical system and what changes might drive the improvements needed in the stroke system of care."
 - a. How do you think the complexities of the healthcare system impact stroke survivors and carepartners?
 - b. Have you encountered any specific challenges or barriers in navigating the system?



Rebuilding Identity and Rewarding Lives

- c. In what ways can advocacy and policy changes contribute to improving the stroke care system?
- d. What role do you think organizations like Stroke Onward can play in advocating for change and improving the stroke care system?