

Identity Theft: Rediscovering Ourselves After Stroke

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Chapter 6 Summary: Let Me Talk!

Two years post stroke, Debra still avoided most big social gatherings. She decides to attend Steve’s college reunion. As a professor, Debra had researched the impact of philanthropy on charter schools. When a discussion on charter schools arose at the reunion, she wanted to share her expertise on the topic. She couldn’t find the right words to express her thoughts. Steve saw her frustration and helped to change topics.

Debra describes how aphasia’s impact on speaking, understanding, reading, writing differs for each stroke survivor. Her challenges are mostly expressive. She struggles to express her thoughts, both speaking and writing. Even though she can construct ideas, words, and even sentences in her head, they often don’t come out correctly. Debra shares how aphasia has changed her life more than her limp and lost use of her right arm. Aphasia forced her out of teaching and altered many of her core roles and relationships in life. Her family often played games of twenty questions to help guess her message. But they couldn’t always figure out what was in her head. Debra is grateful that her thinking is still clear. Social relationships and identity rely heavily on using language. Aphasia can make you feel isolated and withdrawn.

Debra introduces **Trish Hambridge**. Trish was just 45 years old when she had her stroke. Her aphasia kept her from returning to the job she loved as a tech manager. She was known for her sense of humor and found new ways to express this to others. Trish is a tech pro who uses apps and other tools to help her communication. She is determined to continue life as best as she can. Debra tells the stories of several other people to highlight how different aphasia can be for each person. **Sean Maloney** tells how running his company with 15,000 people was “nothing compared to not being able to speak” and the demands of relearning speech. Debra has learned that continued determination and work is key. She says that those who say recovery stops

after 12 months are “flat out wrong”. But even with progress, having aphasia is a constant battle that requires adaptation in how you approach your life. Not being able to share all the expertise she holds in her head or what she cares about, has changed how she relates to people. Yet, relationships are critical to your identity. Debra emphasizes the importance of learning to communicate nonverbally and using other tools. Each person has to find their own set of strategies to help communication. Debra tells how Trish decided to go back into the world. She’s learned to be hilarious again using new tools.

Chapter 6 Highlights: Let Me Talk!

1. Two years after her stroke, Debra still tended to avoid big social gatherings. But she decided to go to Steve's college reunion. One conversation with a group of friends turned to charter schools. Debra had researched this topic as a professor. She could not join the debate and became very frustrated.
2. Aphasia's impact on speaking, understanding, reading, writing differs for each stroke survivor. It's different for each person. Debra says her challenges are mostly expressive. She struggles to express her thoughts, both speaking and writing.
3. Even though Debra can think of words, and even sentences in her head, they often don't come out correctly. Steve described in a CaringBridge post how painful it was to watch Debra's frustration when the wrong words came out.
4. Her family ended up playing many games of twenty questions to help figure out Debra's message. Sometimes they couldn't get to the answer. Her family challenged her to correct her errors when talking together. For Debra, conversation is not only about relationships, but also another focus of rehab.
5. Debra shares how aphasia has changed her life more than her limp and the loss of use of her right arm. Aphasia forced her out of teaching and altered many of her core roles and relationships in life.

6. Debra points out that there are about 2 million people in the U.S. who have aphasia, but it's still little known to the public. She cites speech pathology researcher, Dr. Leora Cherney and colleagues who report, "Those affected by aphasia report social isolation, loneliness, loss of autonomy, restricted activities, role-change, and stigmatization."
7. Although aphasia is a loss of language, not intelligence, the public may not understand. Debra warns that strangers may look at people with aphasia as incompetent, drunk, or childish when they first meet. But Debra is grateful that people with aphasia can still think clearly.
8. Debra explains how important our social relationships are to our identity. But these relationships rely heavily on language. Having aphasia can make one feel cut off from the world.
9. Debra introduces **Trish Hambridge**. Trish was just 45 years old when she had her stroke. Her severe aphasia kept her from returning to the job she loved as a tech manager at Apple. She was known for her sense of humor and practical jokes. She had a close group of friends.
10. Trish was determined to find new ways to express her humor and connect with people. Trish is a tech pro who uses apps and other tools like her cell phone to help her communication. Debra says Trish "owns her identity as an aphasic stroke survivor." She will tell a busy waitress that she has a speech problem, and the waitress will slow down. Trish is determined to continue life as best as she can.

11. Debra shares the stories of several other stroke survivors. Aphasia looks very different for each of these people. **Laura Wang** has the most extreme example of lost communication due to locked-in syndrome. Her language is still intact, but she can't move anything except her eyes. She uses a laser pointer and alphabet board to spell out what she wants to communicate. It is a slow and tedious process.
12. **Sean Maloney**, the Intel Executive, said that learning to speak again was the "most difficult experience" he has ever had. He said running his company with 15,000 employees was "nothing compared to not being able to speak." Both Sean and Debra benefitted from intensive Melodic Intonation Therapy which uses rhythm and melody to help regain speech. Debra also practiced hundreds of Rosetta Stone lessons.
13. Debra has learned that continued determination and work is key. She says that those who say recovery stops after 12 months are "flat out wrong." Progress may feel slow, but Debra's friends who don't see her often can see changes over time.
14. Having aphasia is a constant battle that requires adaptation in how you approach your life. Debra stresses the importance of making deliberate choices. Think about choosing quiet restaurants, small groups instead of big parties, having patience, and compassion for yourself.
15. Not being able to share the expertise she holds in her head or what she cares about, has changed how Debra relates to people. Yet, relationships are critical to your identity. It's vital to find ways to interact and share your values despite the aphasia. Using tone and gestures can help get a message across.

- 16.** Debra quotes speech pathologist and researcher, Barbara Shadden, “If aphasia came with a warning label, I think it should read, ‘Hazardous to identity’.” Debra emphasizes the importance of learning to communicate nonverbally and using other tools. Each person must find their own set of strategies to help communication.

- 17.** Debra tells how Trish decided to go back into the world. Trish misses not being able to quickly crack a joke. But she has learned to be hilarious again using new tools.

Chapter 6 Points for Reflection: Let Me Talk!

1. Debra said she avoided large social gatherings the first couple of years after her stroke. How do **you feel** about **large social gatherings**?

Dislike Going				So-so				Enjoy them!
1	2	3	4	5	6	7	8	9 10

2. Debra quotes another stroke survivor from an article who says, “**When I’m home alone, I don’t have aphasia.**” Do **you feel** this way, too?

Never				Sometimes				Often
1	2	3	4	5	6	7	8	9 10

3. Since the on-set of your stroke, what aspects of your speech and language have **gotten better**?

	Memory		Comprehension
Speech		Attention	Reading
	Writing		Other

4. Language is an important tool for maintaining relationships. How has your **aphasia impacted your relationships**?

Negative Impact								Positive Impact
1	2	3	4	5	6	7	8	9 10

5. Debra says that those who say recovery stops after 12 months are “flat out wrong.” Have **you** seen **continued progress** past the one-year mark?

No Progress			Some				Ongoing Progress		
1	2	3	4	5	6	7	8	9	10

6. What is the **most frustrating** aspect of your **post-stroke challenges**?

7. Adapting and building your own strategies is important for communicating with aphasia. Describe some of **your adaptations** and **strategies**.

8. What was your **most important** take-away from this chapter?