

Chapter 6 Summary: Let Me Talk!

Two years post stroke, Debra still avoided most big social gatherings. She did decide to attend Steve's college reunion. When a discussion on charter schools arose at the reunion, she wanted to share her expertise on the topic. As a professor, Debra had researched the impact of philanthropy on charter schools. She could not 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, and 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 do not 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 could not 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 Aphasia can make you feel isolated and withdrawn.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.

Identity Theft: Rediscovering Ourselves After Stroke

by Debra Meyerson and Danny Zuckerman



Debra says that those who believe 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 has 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, and writing is different for each stroke survivor. Debra says her **challenges are mostly expressive**. She **struggles to share her thoughts, both speaking and writing**.
3. Even though **Debra can think of words, and even sentences** in her head, they often do not 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. Debra's family ended up playing many games of twenty questions to help figure out her message. Sometimes they could not 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 form 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 changed 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 is 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** and **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 and find new ways to include humor.
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 cannot 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 do not 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 is 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 technology and **new tools**.

Chapter 6: Points for Reflection

1. 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				Absolutely	
1	2	3	4	5	6	7	8	9	10

2. Since your stroke, what aspects related to **speech and language** have **gotten better**?

	Memory				Comprehension
Speech			Attention		Reading
		Writing		Other	

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

Disliked Going				So-so				Enjoyed Them!	
1	2	3	4	5	6	7	8	9	10

4. 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 Progress				Absolutely!	
1	2	3	4	5	6	7	8	9	10

5. Language is an important tool for maintaining relationships. How has your **aphasia impacted your relationships with family or other close relationships**? Have you felt both **negative and positive** impacts?

6. **How do you feel about your aphasia challenges today**? Are you **angry or sad** at times? Do you ever **find humor** in your aphasia challenges?

7. What **adaptations or strategies do you use to help you communicate**?

8. What was your **most important takeaway** from this chapter?