

Chapter 9 Summary: Stroke Is a Family Illness

Two years after her stroke, Debra's daughter Sarah gave a speech at her high school. Debra and her husband Steve went to listen. The speech was about Sarah's journey since her mother's stroke. She described the night of the stroke and the initial years that followed.

Right after Debra's stroke, Sarah did not want to reach out for help from friends or teachers. She was afraid that if she did, people would think she was weak. Once she finally opened up to her friends, she felt free. It is not only the stroke survivor that needs help. Those who are close to them need support too. Sarah learned that asking for help is a sign of strength, not weakness. She ends her speech by saying, "no matter how much you can bench press, you always need a spotter."

Sarah's speech was the first time Debra had heard of her daughter's suffering. She and her husband cried during and after the speech. It was painful to hear how difficult Debra's stroke made Sarah's formative high school years. Her tears were also of joy because she realized that Sarah had "found a way to bounce forward."

Entire families are affected by stroke. The way that families are affected changes as time goes on. At first, the family members rally together to get through trauma. This theme is called "**the family as a lifebuoy**." There is also a gap created in the family. This gap takes the place of the role the stroke survivor played. This theme is called "**absent presence**." The gap can shift the roles of every family member, leading to "**broken foundations**." Roles need to be adapted in order to navigate the change together. Changing roles allows families to "**find a new path forward**." The family takes on a new identity. Tremendous effort is required by all family members. One person's stroke affects everyone. Many carepartners experience depression. In this way, "**stroke is a family illness**." The work cannot fall on one family member. Everyone needs to help.

The roles in Debra's family changed after her stroke. Steve became her primary carepartner. He was (almost) always optimistic and patient. Her son Adam took the role of peer. Her son Danny, who was in college, visited home more often to be with her. Her high school daughter, Sarah, took on a more adult role. Debra realized it was important to play the role of Sarah's mother again.

Debra shares the experience of **Malik Thoma**, CEO of a chain of day spas, whose family relationships were damaged soon after his stroke. Malik felt that some of his family members overstepped their bounds in their efforts to manage his medical care. Malik struggled to think positively about his recovery, and this may be because of the bitter relationships with those who were once closest to him. **Mary Jones'** husband struggled to find a new path forward after being a carepartner for 3 years. He sent Mary to her family who put her in a retirement home. Debra notes that neither Malik nor Mary had large families nor close communities and that collapse is more likely when dependence falls upon one person.

Debra describes all the new roles that her husband Steve took on after her stroke: *primary carepartner, emotional coach, motivator, health-care navigator, financial manager, chief logistician, rehab equipment engineer and communicator to family, friends and even her colleagues*. She also shares the importance of the critical support that Steve received from extended family and friends.

As family roles change, stroke survivors must wrestle with their own changing role, which for many of us is a critical aspect of our life and identity. She shares the experience of **Manny Gigante**, who had a stroke at age 29. He initially struggled with his role as a father to his sons. Manny comes to the conclusion, "... mentoring or parenting my son doesn't necessarily mean I have to be in that physical role. I can coach him in ways to be a good person and good human being, not just being a good athlete."

Debra shares the story of **Whitney Hardy**, the daughter of her good friends Molly and Tom. While still in her 20s, Whitney was struck by a car and sustained a severe traumatic brain injury (TBI) a few months after getting engaged to her college boyfriend, Dan. While Dan stayed by Whitney's side for three years during her recovery, he ultimately ended the engagement. While this was devastating for everyone, Whitney's family remains grateful to Dan for all of the support he gave to Whitney for those years.

Soon after Sarah's speech at her high school, Steve pushed Debra to step back into her mothering role. Sarah was planning to attend her Senior Prom and Steve suggested that Debra have "The Talk" with her. Despite Debra's limited speech, she initiated the mother-daughter sex education "Talk" by saying:

Boyfriend ...[long pause]...

"Yeeessss?" (voice rising, half statement, half question)

...[very long pause... then rapid explosion of breath and words]...

PREGNANT NO!!!!

After a lot of laughter, all agreed that Debra delivered the most efficient "mother-daughter talk" in history.

Chapter 9 Highlights: Stroke Is a Family Illness

1. Debra's **daughter Sarah gave a speech** to her entire school **about her journey** in the years **after her mother's stroke**. Debra and her husband Steve attended.
2. **Sarah described** details of her mother's stroke, and **how she herself struggled to reach out for help** after it happened. She **worried** that she would be **seen as weak** if she told her friends how much she was struggling.
3. **Once she finally opened up** to a friend, she said **she felt free**. Her friends "lifted her up from the bottom of the pit." Peers she did not know well even offered to help.
4. Like her mother, **Sarah found the "silver linings" of the stroke**. There has been **more family time**, her **mom laughs more** now, and **Sarah learned to ask for help**. She ends her speech saying, "As every athlete knows—no matter how much you can bench press, you always need a spotter."
5. This was the first time **Debra had heard** about **how much her daughter struggled** after her stroke. **Both Debra and Steve cried tears of pain and also of joy and pride** during and after their daughter's speech.
6. Debra discusses how **"stroke is a family illness,"** affecting every family member. She describes **four themes** that are **found in post-stroke families**, discovered in research done by Gabriele Kitzmüller.
7. The first theme is titled **"the family as a lifebuoy."** This arises immediately after the stroke, when the **whole family unit comes together** to help the stroke survivor.

8. The theme “**absent presence**” describes how the **role of the person in the family who had the stroke is now vacant**. For example, Debra’s role as mother and wife in her family completely changed immediately following her stroke.
9. “**Broken foundations**” refers to how **everyone’s role in the family changes** post stroke. Every member of the family takes on **new roles** in order **to adapt** to the **new normal** they have found themselves in.
10. Finally, the family starts “**finding a new path forward.**” This involves each **family member working within their new role** to make the new family dynamic work.
11. Debra describes the experiences of different stroke survivors and the effects that their strokes had on their families. The family support and reaction to their strokes varied greatly from person to person. The **support that stroke survivors receive** from their **family can positively or negatively impact** their **recovery process**.
12. She describes **Malik Thoma**, CEO of a chain of day spas, who struggled with the **tensions in his family** over his care. It left him with bitter feelings, and he has **struggled to find a positive path forward**.
13. Debra describes how her own family’s roles changed after her stroke. Her husband, **Steve**, **took on many new roles**, including her primary carepartner. Her **children all took on more adult roles** than they had before, stepping up to provide their mother with a level of support that was never needed in the past.
14. Debra tells how **Manny Gigante**, who had his stroke at 29, worried about how he would be a good parent. He realized that “parenting my son doesn’t mean I have to be in that physical role. I can coach him in ways to be a good person and good human being, not just being a good athlete.”

15. Debra shares the story of **Whitney Hardy**, the daughter of a family friend who was hit by a car in her twenties. She sustained a traumatic brain injury (TBI). Her **fiancé at the time supported her** in her recovery, but eventually he **decided he could no longer marry her**.
16. Although this was devastating for the entire family, Whitney's parents were **appreciative that her former fiancé supported her** as long as he did. They felt that **his support made a positive impact** on her recovery.
17. Sarah's speech made **Debra** realize she **needed to start playing a more active role as Sarah's mother** again. She decided it was time for her and her daughter to have **"The Talk" before Sarah went to her senior prom**.
18. With her limited speech, Debra's talk did not go as planned, but it was a positive experience for Sarah, Steve, and herself. Her **bottom line was telling Sarah, "PREGNANT....NO!!!"** They all laughed aloud together, and "agreed that she had just **delivered the most efficient mother-daughter talk in history.**"

Chapter 9: Points for Reflection

1. Debra talks about how her daughter, Sarah, struggled post stroke. **How many of your family members have told you about how your stroke has affected them?**

None One A Few Most of Them All of Them

2. Sarah received so much **support** once she opened up about her struggles. **How much support did your family receive from others after your stroke?**

No Support Some Support A Lot of Support
1 2 3 4 5 6 7 8 9 10

3. Debra describes how many **family roles** change after someone has a stroke. How much has it felt like the **roles in your own family have changed?**

Not at All Somewhat Changed Changed Quite a Bit Completely

4. Steve is the person in Debra's life who accepted the role of **primary** carepartner after her stroke. **Who took on this role in your life?**

Partner Child Parent Friend Someone Else

5. Debra says, "**When dependence falls on one person, collapse is far more likely. Support needs to be spread widely among family members.**" In **your experience**, have support needs fallen **mostly on one person** or are they **spread more widely?**

6. Debra describes the experiences of other stroke survivors, and how their family's support (or lack thereof) affected their recoveries. **How do you feel that your support system affected your recovery?**

7. Sarah discusses in her speech the "silver linings" for herself, her mother, and her entire family after her mother's stroke. Has your family found any "silver linings?" If so, what are they?

8. Debra describes how her **role as a mother to her daughter has changed** since her stroke. How **has one of your roles or identities in life changed** since your stroke?

9. Sarah shares her lesson: "I learned that asking for help isn't a sign of weakness but a sign of strength." Share at least **one example where you decided to ask for help**, even though it was hard.