

## **Chapter 10 Summary: Partners and Intimacy**

Debra shares the challenges she faced with Steve and their relationship six months post stroke. Steve had regained a sense of normalcy in his life at work, whereas Debra did not. Debra experienced a constant internal battle about wanting and not wanting Steve's help. This resulted in frequent bouts of anger and resentment. Debra tried to show her appreciation. Steve learned he could not support Debra if he put his own needs on hold. Debra knew she was mad at her situation and not at Steve, but it took a toll on their marriage. They would have to work hard to evolve their partnership.

Right after a stroke, the focus is almost all on the survivor. Not everyone has a partner, but for those that do this imbalance puts intense demands on the closest carepartner. It affects the relationship dynamic for many couples.

**Julia Fox Garrison** and her husband struggled with her terrible mood swings and with role changes. Julia realized she wanted her husband to be a partner, not a nurse. They had to switch their focus to opportunities rather than limitations. **Malik Thoma**'s relationship with his wife plummeted, but their relationship was also strained before his stroke. **Randy Miller** and his wife Rose decided when it came to his recovery, "It's not one of us; it's both of us." Rose chose the term carepartner over caregiver. **Deidre Warren**'s physical disabilities remain significant, so she is dependent on her husband, Mike. Yet, Mike's anger is at the stroke, not Deidre. **Andrea Helft** struggled with body image issues and lost interest in sex. **Gail Rusch** lost her sense of confidence in her attractiveness but was reassured by her partner that he loved her for who she was now. Debra emphasizes that despite physical and mental challenges, sex lives can still be fulfilling for a couple post-stroke.

Aphasia continues to be the biggest challenge in Steve and Debra's relationship. It takes a long time for Debra to get her message out, so listening takes more patience. They both can get frustrated. But Debra appreciates that Steve is a "look forward, not backward" kind of person. They continue to work through their issues with honesty and as a team.

## **Chapter 10 Highlights: Partners and Intimacy**

1. Six months after Debra's stroke, **Steve was back at work. Debra's days revolved around as much outpatient therapy as possible.**
2. **Debra found frustration and resentment building.** Sometimes Steve helped too much, other times not enough. He felt like he could not get it "right." This **dynamic took its toll on their marriage's foundation.**
3. Debra explains that a **stroke will challenge a couple** in caregiving, but also **in every aspect of the relationship:** emotional support, roles in the household, financial stability, attitudes, and sex.
4. After the stroke, most of the **focus is on the survivor.** The carepartner faces huge demands and changes in roles. This causes fear or interference with other obligations. **Carepartners often put parts of their own lives on hold.**
5. Kitzmüller and colleagues found in their research that **many marriages did not survive the stress** of the stroke. Sometimes the survivor did not want to limit their healthy partner's life, or their partner was unwilling to change their role in the relationship.
6. Almost 50% of all marriages in the U.S. end in divorce. Relationships are difficult and complex. It makes sense that after a stroke, **partnerships will require even more work to evolve and thrive.**
7. **Stroke survivors** who navigate their recovery **without a partner face an even harder road.**
8. Debra talks about different stroke survivors and their relationship and intimacy experiences:

1. **Julia Fox Garrison:** Julia faced challenges such as **terrible mood swings due to her medications**. This **caused strains on her relationship**, as well as the change in roles. She realized that she wanted her partner back as a husband, not as her nurse. They worked hard to **figure out how to reconnect sexually as a couple**.
2. **Malik Thoma:** After his stroke, the effect on his marriage was “devastating.” He and his wife also struggled before the stroke. They seem **stuck resenting each other** instead of finding a new path forward.
3. **Randy Miller:** Randy and his wife Rose made a concerted effort to move beyond the patient and caregiver dynamic to make sure that their relationship would stay balanced. She **decided to use the term carepartner instead of caregiver**. Despite his severe aphasia, he managed to order flowers for their anniversary. They cherish time together, be it mowing the lawn or making love.
4. **Deidre Warren:** Deidre is dependent on her husband Mike due to her physical disabilities. Although her **dependence can be frustrating**, Mike is grateful that he has the ability to help Deidre. He **feels the loss of their retirement plans**. He is angry at her stroke, not her. Mike has also **rediscovered what made him fall in love with his wife**.
5. **Andrea Helft:** Andrea was a recreational athlete at the time of her stroke. Her **stroke impacted her self-image** and confidence in returning to intimacy. She **lost her interest in sex**.
6. **Gail Rusch:** Gail **felt unattractive after her stroke** which impacted her interest in intimacy. Her sweetheart’s reassurance that he loved her as she was, **changed her mind about intimacy and self-image**. It is a good reminder that **our identities are often influenced by those closest to us**.

9. Kitzmüller's research promoted **the value of peer groups** where people can **share common stroke experiences** and **expand their social network**. **Couples that thrived looked forward**, not backward. These couples **focused on opportunities not limitations**.
10. Steve got good advice: he had to take good care of himself in order to take good care of Debra. **Debra is happy to encourage Steve to do things he loves** like skiing or long bike rides with friends. But she admits that **she often misses getting to join him**.
11. Debra points out that **small gestures of appreciation** can go a long way. She **looked for ways to show Steve she cared** and appreciated his efforts.
12. Steve and Debra have not pursued counselling since her stroke. They have **pulled on insights and tools** from the **two other times** they had **counselling before her stroke**.
13. Debra considers herself lucky that her **enjoyment of sex improved after the stroke**. She doesn't know why, but it's a silver lining. Steve thinks **being less stressed helped her**.
14. Debra says that **emotional and psychological factors are often bigger barriers** to resuming sex than physical limitations. Couples may wonder: "Is sex safe?", "Am I still attractive?", "Can I be both a caregiver and a lover?" According to the experts, even though you may need to make adaptations due to physical changes, **stroke survivors and their partners can usually recreate a healthy, fulfilling sex life**.
15. Researcher Meghann Grawburg from New Zealand reports that **stroke survivors may report less frequent sexual intimacy**. However, she found it was often **replaced by other forms of physical intimacy**.

16. Aphasia remains the biggest ongoing challenge in Debra's partnership with Steve. Debra has challenges in expressing herself and it takes more patience to listen to her.
17. Debra explains that some of what helped her relationship with Steve was simply "good luck." He tends to be a "look forward, not backward" kind of person. He has a positive and problem-solving approach.
18. Debra admits that now and then, his positive outlook can drive her crazy. When she is struggling and mad at the world, it can feel like Steve does not see how hard it is. Debra and Steve still face challenges, but they work through those with honesty and togetherness, in an always evolving relationship.

## **Chapter 10: Points for Reflection**

1. Debra explains that after her stroke she often directed **frustration towards her husband** even though she was mad at the situation and not at him. Did **you ever express anger** and **frustration towards someone** you cared about, even though they were not to blame?



2. Debra states, "A stroke will challenge the pair not just in caregiving, but in every aspect of the partnership." **What aspects of your most important relationship(s) have changed?** (Circle all that apply)

Financial

## Responsibility

Social

## Intimacy

## Attitudes

## Roles

## Other

3. Debra explains that while **you may need to make adaptations due to physical changes**, stroke survivors can usually recreate a healthy sex life. Did you receive **adequate support** and **information** about **intimacy** and **sex after your stroke**?

## Not at All

## Some information

A Lot

1 2

3

4

5

6

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6

10

4. Sometimes **Debra wanted more help** from Steve, other times she wanted **less help**. It was **hard for Steve to know** what to do. Have **you ever found yourself** in this **dilemma with a significant person** in your life?

Never              Rarely              Sometimes              Fairly Often      All the Time!

**5. Relationships continually evolve. Are you still learning about what works best with your partner or other important relationships after your stroke?**

6. In the book, Debra says that “Steve got good advice; he’d be no good as support for me if he didn’t take care of himself.” **What can you do to help your carepartners take care of themselves?**

7. Debra says she's lucky that Steve is a "look forward, not backward" type of guy. **Why is this a helpful outlook** after stroke? **Describe someone in your life who has this attitude.**

**8. Relationships** are **complicated** and can be **difficult**, even without the stress of a traumatic event. **After your stroke**, did you feel like your **relationships with loved ones improved** or do you feel **less connected**? Has this feeling **changed over time**?

9. Debra tried to express appreciation to her carepartner in a variety of ways. **What are some ways you have expressed appreciation** to your main carepartner?