

## **Chapter 1 Summary: A Slow Fall Off a Cliff**

On Labor Day weekend of 2010, Debra and her husband Steve headed to Lake Tahoe with their son, Danny, daughter, Sarah, and their dog, Kaya. They looked forward to a relaxing weekend before Debra started teaching fall classes at Stanford. But something felt wrong with her leg, and she had a bit of a headache. When they took a favorite hike, it was too hard to walk so they had to turn back. They returned to the cabin so Debra could rest. By the next morning, her headache was worse. Both her right hand and leg were feeling weak. Steve knew something was wrong and insisted they head to the hospital. A CT scan showed she had a stroke. Debra was quickly sent to a larger hospital in Reno. Her family was scared. Overnight, her symptoms slowly progressed. They called it, “her slow motion fall off a cliff.” They did not know what was causing the stroke. They would learn later that she had a small tear in her carotid artery. Watching her condition get worse by the hour, Steve felt helpless. By morning, she could not move the right side of her body or say any words—or even make a sound.

As soon as she was stable, Debra was flown to Stanford Hospital and admitted directly to the ICU. Her mom flew from Los Angeles to be with them. Her middle son, Adam, flew home from college in Boston. They put a feeding tube in her nose since she could not swallow. Debra was now one of the 800,000 people a year who have a stroke—and just 25% of those are 65 or younger like Debra. Debra describes the way five different stroke survivors experienced the first symptoms of their stroke. She remembers how she felt in those early days—helpless, scared, confused, and broken. Debra got angry when she heard doctors talking in the hall with Steve. She wanted to be included. Debra wanted to know about the “outside world” to help her feel more connected. During a visit with her brother in the ICU, he told her a funny family story. Suddenly, she made a noise like a laugh. Her first sound. That was a good sign. But alone at night, Debra wondered how she could live a life without speech.

## Chapter 1 Highlights: A Slow Fall Off a Cliff

1. On **Labor Day weekend, 2010**, Debra and her **husband, Steve**, headed to Lake Tahoe for a relaxing weekend. Debra would soon teach fall classes at Stanford again. They **went with** their young adult son, **Danny**, teen daughter, **Sarah**, and dog, **Kaya**. Their middle son, **Adam**, was not with them. He was in Boston to start college.
2. **Debra's right leg was feeling weird**. When they got to Tahoe, **Debra thought a good walk would help**. She was **surprised that her leg felt weak**. She **could not step normally**. They had to go **back to the cabin**. **Debra had a mild headache too**.
3. The **next morning**, her **headache was worse**. **Steve noticed it was hard for her to use her right arm** to pick up the aspirin. **Steve saw signs of stroke: right arm, right leg, headache**. **Debra argued when Steve said it was time to go to the hospital**.
4. Debra **started off at Tahoe Forest Hospital**, but the **CT scan showed** Debra had a **stroke**. The doctors sent Debra to **Renown Hospital** in Reno by ambulance. Her **family tried not to panic**. What did this all mean?
5. **Doctors did more tests** at the Reno hospital. Debra's **speech was starting to slur**. The **doctors could not tell the family a lot about why this stroke happened** or what to expect.
6. **Adam flew home** from college right away. **Adam knew a stroke was serious**. **Daughter Sarah did not know how bad strokes could be**. Strokes were **new to her**.
7. **Debra cannot remember much** from those early days. **Family tells Debra she was frustrated**. They **remember being scared**.

8. **Debra explains** that **recognizing the signs of stroke is critical**. She explains: **FAST**. **Face** = look for an **uneven smile**, **Arm** = one **weak arm**, **Speech** = **slurred speech**, **Time** = **Call 911** right away. Depending on the type of stroke, the **drug tPA** can help **break up a clot**, **BUT you must take it within 4 hours of your stroke**. There are new surgical ways to break up a clot too.
9. Later on, the **family would learn** that a **small tear in Debra's carotid artery shut off the blood flow to her brain**. This was **not a common cause of a stroke**. There was **no warning**.
10. Between Sunday evening and Monday morning, **Debra's symptoms got worse** by the hour. **Steve felt helpless**. They **describe that night as her "slow motion fall off a cliff"**. By the morning, her **arm and leg were paralyzed**. Debra **could not say a word** or even cough. She **could not respond**, but **Steve felt she was "still there."**
11. **Debra was stable enough** to be **flown to Stanford**. They **wanted to be close to their home**. Her **mom flew from Los Angeles to meet them** at the hospital.
12. **Debra had complications that kept her in the ICU**. There were **no clear answers** as to why she had the **carotid artery problem**. Her stroke was not typical—but **each stroke is unique**. She **needed a feeding tube** in her nose for nutrition.
13. Her **family felt frustrated and scared**. They were **not used to seeing their strong, active mom unable to talk or move**. **Debra's mom remembers feeling devastated and terrified**. It was so **hard to see her daughter**

helpless.

14. **Debra was one of 800,000 people** who have a **stroke in the U.S. each year. One of every four strokes happen in people like Debra age 65 or younger.** Many have no traditional factors or history. Many **strokes are misdiagnosed** at first as a **headache or dehydration.**
  
15. Debra introduces **4 stroke survivors** and shares their stroke stories:
  1. **Isaiah Custodio:** He was at football practice when he experienced a very bad headache, then vomited and fainted. Isaiah was only 13 years old.
  2. **Kathy Howard:** Her stroke happened on her 31st wedding anniversary. She saw a black hole on the TV screen, threw up, saw red and green.
  3. **Sean Maloney:** He was to be Intel's next CEO. His stroke was sudden, but he describes it as peaceful. He thought "That's it, I'm gone."
  4. **Cindy Lopez:** She thought she was fine and thought her husband was making a fuss. It took her two days to realize that she could not move parts of her body.
  
16. **Debra remembers** how the **uncertainty and lack of control** was **unbearable.** She **felt helpless, confused, and broken.** If she heard **doctors talking with her husband without her,** she **got angry.** She **wanted to be included.**
  
17. While in the ICU, **Debra liked hearing** about **stories "of the outside world."** It **made her feel** more **connected.** Her **brother told her a funny story. Debra made** her **first sound,** like a **laugh.** That was a **good sign.** They tried hard to come up with other stories to make her laugh. But **alone at night, Debra wondered** what **life without speech** would be like.

## Chapter 1: Points for Reflection

1. Debra did not realize that the “funny” feeling in her leg could be a sign of a stroke. What were the first **signs of your stroke**? (Circle all that apply.)

Lost Consciousness

Speech Problems

Swallowing Problems

Numb Face

Headache

Weak Leg or Arm

Vision Problems

Other

2. Debra cannot remember the early days of her stroke. How well **do you remember** those first days after your stroke?

Little Memory

Some Memory

Full Memory

1

2

3

4

5

6

7

8

9

10

3. Debra felt the **uncertainty** about her recovery was very **stressful**. Were **you worried** about your **recovery** in those early days?

Very Worried

Somewhat Worried

Not Worried at All

1

2

3

4

5

6

7

8

9

10

4. Debra describes her stroke as, “**a slow fall off a cliff.**” How would you **describe your stroke**?

5. It took a while for Debra’s medical team to figure out what caused her stroke. How **easy or hard** was it for your doctors to figure out **what caused your stroke**? What were **you told** was the **cause**?

6. At first, Debra was completely unable to speak—she could not even nod her head yes or no. What was **your speech** like right after your stroke? What do you remember about your **first sound or words**?
  
7. Why did Debra **get angry** when she heard the doctors talking to her husband in the hall? Did **you have frustrating experiences** while in the hospital?
  
8. **Debra was scared** that the lack of speech would cut her off from the people she loved. What were **your first feelings** or thoughts about your **communication changes** after your stroke?
  
9. **When did you first hear** the term “**aphasia?**” Did you understand the term or was it **explained fully** to you?