Josie’s Story by Sorrel King

A guide for book clubs

Prepared by the Josie King Foundation

Josie King Foundation at BCF
creating a culture of patient safety, together

www.josieking.org
Thank you for reading *Josie’s Story* and for choosing it for your book club. I hope you enjoyed the book and found it to be informative, educational and inspirational. The book has sparked many conversations across the country - not only in hospitals, medical schools, and nursing schools, but in living rooms and coffee shops where people are coming together to talk about Josie’s story and its impact on the health care industry and people’s lives.

I have prepared some background material and some topics for discussion in hopes that it might add to your book club’s experience - a conversation based on questions that I am frequently asked and suggested topics for discussion. Enjoy a cup of tea, a ham biscuit or two, pour yourself a glass of wine and settle in for what I hope will be an illuminating conversation.

We have set up a space on our online forum at www.josieking.org for readers to share their thoughts about *Josie’s Story*. Feel free to visit our website, and talk with others about the book.

Thanks again for reading *Josie’s Story*.

Sincerely,

Sorrel King

Baltimore, Maryland
October 2009
Why did it become important to you to tell Josie’s story now in book form?

So many other people had been telling Josie’s story-sometimes not always getting it completely right. There was also so much more to the story: so many strange things that happened; so many interesting people I was meeting; places I was going; things I was learning. Good things were happening as a result of her death and I wanted to share them.

For me writing the book was meant to be. Sometimes the words would keep me up at night until I turned on the light and wrote them down. There were times when it seemed to write itself. It had become apparent to me from the beginning that her story was having a positive effect on health care providers and I thought that perhaps if I told more of the story that she could have an even bigger impact: reaching the general public and educating them; helping parents who have lost a child; really just helping anyone who has suffered any type of loss. In the end it is a story about decisions- trying to make something good come out of something bad.

You have succeeded in changing the deeply ingrained medical culture in the United States. What gave you the strength and insight to accomplish this?

When Josie died I knew from that very moment that something big was going to happen. It was not going to be a garden or a bench or a plaque with her name on it. It was going to be something REALLY big. I was just not sure what it would be. It took a long time to figure it out. I would say that the energy from my grief and anger gave me the strength to find what I needed to do.

As far as having the insight, I am not sure how insightful I was. I did not put a whole lot of thought into how I was going to go about preventing medical errors. I am not a doctor or a nurse and I knew absolutely nothing about the health care industry. All I knew was that Josie died from medical errors- a breakdown in the system- poor
communication and I was determined one way or another to prevent that from ever happening to anyone else. I just kind of jumped in headfirst and tried to figure it out along the way.

**Do Americans fully understand the pervasive problem of medical error? What more do they need to learn?**

We hear stories in the news and we hear statistics, but I don’t think people are as aware of the problem as they are of cancer or AIDS or other diseases. It’s been ten years since the Institute of Medicine issued the landmark report – “To Err is Human” – documenting the prevalence of medical errors and estimating that upwards of 98,000 Americans die each year because of preventable medical errors. I’m not sure the numbers really hit home. When a plane crashes it is all over the news and rightly so. The frequency of deaths from medical errors is like a jumbo jet crashing every day. That analogy alone seems to make it more real for people.

But grasping the scope of medical errors is just the beginning. Patients should be aware that great strides to make health care safer are being made. It’s a very exciting time for patient safety. Hospitals all over the country are doing amazing things to prevent medical errors.

Patients should also trust their health care providers. No doctor or nurse means to harm a patient, but patients need to understand that it is a complex system that can sometimes break down. Patients and their families need to pay attention and be involved in their care as much as they feel comfortable with.

**In Josie’s Story you write about how you were surprised to find that doctors, nurses, and other health care professionals also were suffering in silence when a medical error occurred?**

After Josie died, I was so consumed in my own grief and anger that I could not put myself in the shoes of the doctors and nurses who had cared for her. About a year or two later, I received a letter from one of her doctors. The letter was heartfelt, filled with emotion and made me see things from a different perspective. It made us realize that I was not the only one who was suffering from the loss of Josie. It was really the first time I was able to step out of my own sadness and begin to think about other people and how they had been affected by Josie’s death. This realization led to a research project called Care for the Caregiver, which led to the creation of the
In Josie’s Story, you write that your methods of trying to manage your grief differed from those of your husband, Tony. How deeply did this threaten your marriage?

It was hard. I had to talk about Josie’s death over and over again. I cried all the time. I couldn’t sleep. I expected Tony to react the same way, but he reacted in a totally opposite way. He kept it all in. It was really hard for me to understand. The grief books say that men and women grieve differently and they are right. It took me a long time to figure that out, but when I did I realized that he was suffering as much as I was; he just dealt with it in his own way and I had to accept that. I think some of it was him just trying to stay strong for me.

We were both so sad that neither one of us could help the other. It was like we were both sinking. We would look at each other and see our own sadness. A lot of marriages don’t survive the death of a child and I guess it is because sometimes you just want someone there for you who is not feeling your pain and who can help bring you back. We knew that we were going to have to get through it together and we knew it was not going to be easy, but we stuck it out and survived. I think in the end perhaps our marriage is stronger for it.

What would you tell other parents struggling to help their children who have lost a sibling? Did you find certain routines or words helped your children heal after Josie’s death?

The thing that worked for us as a family was just staying close and hunkering down. We spent a lot of time together. Tony and I tried to talk about Josie as much as we could even though it was painful. We did not want the children to think she was no longer a part of our lives. We also tried to keep their routines of school, friends, and sports as normal as possible. I had a hard time letting them out of my sight in the beginning. Instead of them going to friends’ houses, they all came to ours. I remember telling them a few weeks after Josie died that she would always be in their hearts and that she would help them when things got hard.
You have taken a long journey from Josie’s bedside, through intense emotional pain, to create the Josie King Foundation and stand before convention halls filled with medical professionals to fight for a safer health care industry. What has been most rewarding to you personally?

The e-mails from nurses and doctors around the world telling me that Josie’s story is changing the way they care for their patients; that her story is making our health care system safe. The most rewarding thing of all is that her story is saving lives.

**What is the single most important message that you hope people take away from reading Josie’s Story?**

We will all suffer from some sort of loss or disappointment during our lives. It may be death, cancer, divorce, loss of a job, bankruptcy or just a bad day. If we can somehow find a way to make something good come from that loss, that disappointment then we not only help ourselves but we can help others and by helping others we help ourselves all over again.
For Discussion

1) Were you aware of the problem of medical errors before reading Josie’s Story?

2) When a loved one or you are in the hospital what will you do differently after reading Josie’s Story?

3) Why was Sorrel unable to understand the minister’s emphasis on forgiveness when she first visited him, or during his sermon after 9/11? Would you be able to forgive someone who was responsible for the death of a loved one?

4) How did you react to the letter from the pain management doctor?

5) What did you think of Sorrel’s attempt to “find religion”? Why did she want it? Could you relate and sympathize? If she had had a firm religious background/belief would it have helped her? If so, how?

6) Sorrel writes a great deal about grief. Did you gain any insights into the grieving process from the book? What did you learn?

7) Did you find parts of the book to be humorous? How did those moments make you feel?

8) Sorrel discusses how writing helped her - both in managing the information about Josie’s care when she was in the hospital, and in grappling with her emotions after Josie’s death. Do you find writing to be therapeutic?
9) What characters in the book stood out for you?

10) Did you find this book uplifting?

11) Josie’s Story is framed by two family scenes- one at the beach before Josie’s death and one on the ski slopes after. What do these two bookends tell us about the journey of life?

12) Do you think a person can make a difference in the world we live in?