

Q&A with author Lois Kelly

Why did you write this book?

I wrote **Be the Noodle** to help people deal with the crazy things that no medical, hospice or traditional how-to-deal-with-end-of-life books address. From the gut wrenching, like not being able to call 911 during a crisis once you sign up with hospice and struggling to be kind and helpful when you feel like a sleepless shrew, to the mundane, like dealing with too many banana breads from well wishers and advocating for patient martinis with the oncologist.

The idea for the book started while I was caring for my mother during the last three months of her life. I started blogging at night about what was happening. I blogged to keep my family updated and to keep my sanity. The response to the blog was amazing. People wrote me and said, “This is exactly what I am going through. Thank you for being so honest.” And “Boy, I wished I could have read this when I was caring for my parents.” I realized that I needed to write this book to help all others.

I also wrote it because my mother told me to. “Why don’t you turn all this little writing into a book so we can help someone else going through this,” she said a few weeks before she died. With one exception, explained in Chapter 39 (Morphine & Other Medical Dilemmas”), I obeyed my mother.

Who’s the audience for the book?

Anyone who has, is, or might soon be in the position where they need to help someone near the end of their life. And that “anyone” is a big tribe. An estimated 50 million Americans are caregivers, according to Carolyn Vachani, RN, MSN, AOCN at the University of Pennsylvania’s Abramson Cancer Center. With the aging baby boom generation that number is growing rapidly.

The Abramson Center research has also found that:

- Approximately two-thirds of caregivers are women.
- 85% of caregivers found the satisfaction of caring for their loved one to outweigh the disadvantages.
- Not surprisingly caregivers report higher levels of insomnia, anxiety, poor appetite and depression than non-caregivers.
- The estimated economic value of family care giving in the U.S. alone is \$300 billion

The book’s secondary audiences are hospice professionals, therapists, and religious counselors.

What do you hope readers will take away from it?

I hope that this book helps readers stay sane, find super powers they never knew they had, and know that they are not alone. Most of all I hope the book shows people how to become stronger from helping someone die and find deep fulfillment in doing something that most people want to run away from. Don't run. The rewards are too big.

Why would anyone want to read about helping someone die? Kind of a depressing topic, isn't it?

Surprisingly, helping someone during their final months can be inspiring and rewarding in ways you never thought possible. When re-entering every day life after helping someone die, you are a stronger, more confident, more grateful person. This was my first-hand experience, and many caregivers have told me that they found the same thing. After being able to help someone die we gained a self-confidence to be able to take on small and big challenges at work, at home and in pursuing new interests.

So while this book is about dying, it's also about finding possibilities.

Why do you say in the introduction that the book is “caregiver’s adventure guide”?

An adventure is defined as an experience that can be both terrifying and inspiring because you enter into a flow that is nothing like you've experienced before. Helping someone die can be one of life's greatest adventures. But like all adventures it can be scary and a travel guide from a native helps navigate the adventure. While we as a society revere “experts,” native knowledge is as helpful. Maybe more so.

In reviewing the book Dr. Bernie Siegel said, “This is a book written by a native. It combines and expresses the wisdom of the head and the heart in a way that will help any caregiver no matter what problem they are confronting. I have experienced all that Lois Kelly writes about on a personal and professional level and her short, easily understood lessons are a gift to us all.” Natives see things professionals sometimes do not.

What does the title, “Be the Noodle,” mean?

My mother was a strong, independent woman who liked to swim far out into the ocean. She thought people who used swimming noodles for “extra help” were “ridiculous.” But in the final months of her life she knew that she would have to hold onto a metaphorical noodle -- and that noodle would be her family and friends, helping her stay buoyant despite unpredictable currents, pulling her to safety when she could no longer paddle. So the first lesson in the book is “Be the Noodle.”

Also many people are so afraid of helping someone die. I wanted a title that showed people not to run away, but stand up and “Be the Noodle.” It’s not as hard as people fear.

This book is part memoir, part “how-to” advice? Why this format?

From my long career in marketing I know that we all learn best from stories. Stories engage us in emotionally journeys, and this emotion is what inspires us, motivates us and helps us learn. At the same time, people like a little help in taking away the point of a story, which is why I sum up each chapter with a lesson based on the story.

What’s your favorite of the 50 chapters/lessons?

I have three favorites:

1. **“*Private Benjamin Reporting for Duty*”** because as a care giver you do feel like the 1980 movie character Private Judy Benjamin who admits that she is “29 years-old and qualified for nothing.” When you enlist to care for someone with a terminal illness you feel like you’re qualified for nothing. I also like dissing the war metaphors used in business in sports. But unlike those fields, care giving is life or death and the war metaphor, a la Judy Benjamin, is perfect.
2. **“*Enough with the Banana Bread*”** because dealing with well-wishers can be as trying some days as caring for the ill person. People who’ve been through a caregiver adventure burst out laughing when they read this chapter. In some parts of the culture it’s a banana bread problem, others experience lasagna or casserole bombardment.
3. **“*Hurry Up and Die*”** because know one ever talks about how you feel towards the end, when your compassion is stretched to the max and you feel so, so guilty for praying that the person you love will hurry up and die. It’s a taboo topic that I think needs to be acknowledged.

What was the hardest part of caring for someone with advanced cancer?

No surprise, the hardest part for me was the end of the journey, when I was laid off from the caregiver job I never wanted and had no training to do. Even though towards the end of Bette’s life I had days where I wished she would hurry up and die because she was suffering and we caregivers were spent, it was such a sad day when she did. This seems to be a shared experience among caregivers. At last it’s over. Then, pow, Rambo grief kicks you in the gut.

I urge people to be part of the journey and find time to be with the person they love. Care giving days may be long, but life is short.

For more about care giving, Be The Noodle, or Lois, go to www.bethenoodle.org.