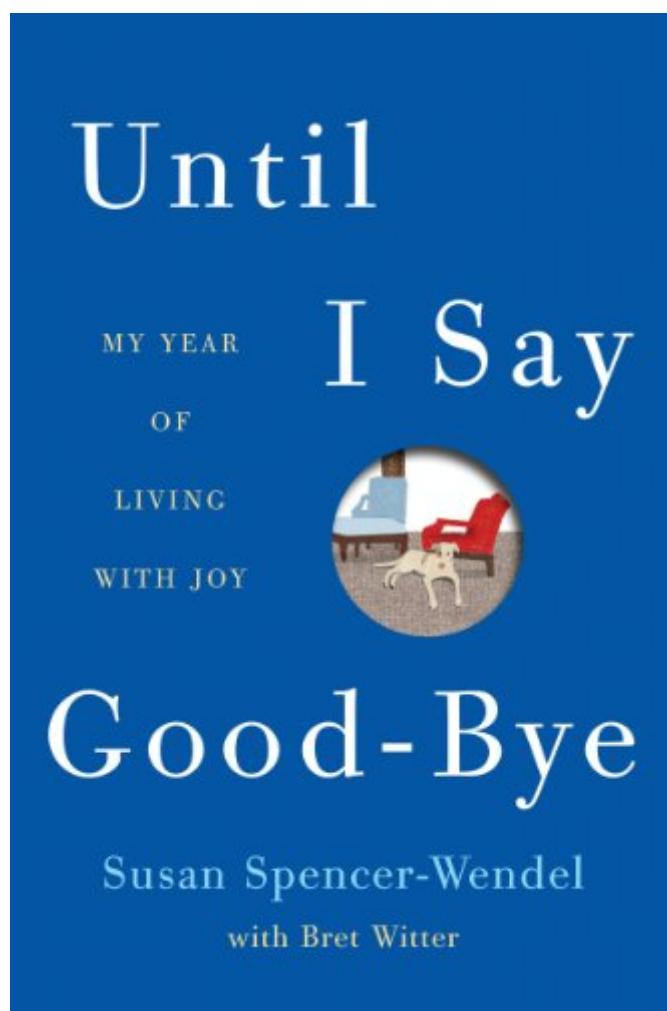


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Until I Say Good-Bye: A Book About Living



Synopsis

In June 2011, Susan Spencer-Wendel learned she had amyotrophic lateral sclerosis (ALS)â "Lou Gehrig's diseaseâ "an irreversible condition that systematically destroys the nerves that power the muscles. She was forty-four years old, with a devoted husband and three young children, and she had only one year of health remaining. Susan decided to live that year with joy. She quit her job as a journalist and spent time with her family. She built an outdoor meeting space for friends in her backyard. And she took seven trips with the seven most important people in her life. As her health declined, Susan journeyed to the Yukon, Hungary, the Bahamas, and Cyprus. She took her sons to swim with dolphins, and her teenage daughter, Marina, to Kleinfeld's bridal shop in New York City to see her for the first and last time in a wedding dress. She also wrote this book. No longer able to walk or even to lift her arms, she tapped it out letter by letter on her iPhone using only her right thumb, the last finger still working. However, Until I Say Good-Bye is not angry or bitter. It is sad in partsâ "how could it not be?â "but it is filled with Susan's optimism, *joie de vivre*, and sense of humor. It is a book about life, not death. One that, like Susan, will make everyone smile. From the Burger King parking lot where she cried after her diagnosis to a snowy hot spring near the Arctic Circle, from a hilarious family Christmas disaster to the decrepit monastery in eastern Cyprus where she rediscovered her heritage, Until I Say Good-Bye is not only Susan Spencer-Wendel's unforgettable gift to her loved onesâ "a heartfelt record of their final experiences togetherâ "but an offering to all of us: a reminder that "every day is better when it is lived with joy."

Book Information

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Customer Reviews

The sickest she'd ever been was "after I ate a bad chicken sandwich in South America." And now her left hand doesn't work. Susan Spencer-Wendel lives in reality --- she's a veteran journalist for the Palm Beach Post. It doesn't take her long to figure out she has amyotrophic lateral sclerosis (ALS): Lou Gehrig's disease. She's married, with three young kids. She's 44 years old. She has a year to live. And not a pleasant year. Muscles weaken. Walking becomes impossible. Then swallowing becomes a challenge. Then breathing. In the end, the patient finds herself trapped in a non-functioning body, waiting to die. HarperCollins paid \$2 million to publish "Until I Say Good-Bye" and Universal paid another \$2 million for the movie rights, and neither did it so they could present a chronicle of death at work. Their reason is right in the subtitle: "My Year of Living With Joy." Because that was her resolution. Not to commit suicide before she couldn't. Not to despair. But to spend her time wisely: "To take the trips I'd longed to take and experience each pleasure I'd longed for as well. To organize what I was leaving behind. To plant a garden of memories for my family to bloom in their futures. Lou Gehrig was an athlete. ALS took his talent immediately. But I was a writer. ALS could curl my fingers and weaken my body, but it could not take my talent. I had time to express myself. To build a place of my own with comfy chairs, where I could think and write and sit with friends. Where I could wander through my own garden of memories and write them down. A wandering that became, beyond my every fantasy, this book. A book not about illness and despair, but a record of my final wonderful year. A gift to my children so they would understand who I was and learn the way to live after tragedy: With joy. And without fear. If Lou Gehrig could feel lucky, then so could I. So should I." It's hard to know what to say about this book. Really, it's beyond criticism. To write anything negative isn't to comment on its literary merits, it's to dish Susan Spencer-Wendel's life. And you can't. All you can do --- if you can read this book at all --- is to turn the pages, slack-jawed, in awe at her insistence on having powerful, individual experiences with her husband, her kids, her sister, her best friend and the birth mother she's only recently met. It seems impossible, but she gets around: the Northern Lights, Budapest, swimming with dolphins. As I read this book, I discovered something unnerving: I was reading two books. One is the book she typed

on an iPhone with her right thumb, the book Bret Witter then polished for her. The other is my book, the one I'd write if I knew I had a year to live. I'd like to think I'd have a short, private cry, then get on with my life. Not as a stoic, but because I understood that we're all dying, and the only difference between everybody else and me was that I more or less knew when. I'd like to think that's some kind of advantage. And I'd like to think Susan Spencer-Wendel's final wish would be mine: "To make people laugh and cry and hug their children and joke with their friends and dwell in how wonderful it is to be alive." How utterly soppy. How totally terrific.

I enjoyed this book on many levels. Originally having taken care of patients with ALS, I was curious to see how Susan kept from becoming a frightened bitter person. I did see a frightened woman who demanded to live her remaining days, her way. To connect herself indelibly to her roots and her loved ones. The journey she takes completes her. She makes memories for each of her children, husband, family and friends? She is reverent and irreverent at the same time. Also ever aware the activity she is choosing will cause the ALS to advance, even faster. I was delighted to see a person that is able to say death is coming but I will enjoy each day God gives, to the fullest. I cry when the tenderly thought out excursions for her children, do not go as she would like, because the memories are her dreams and her children have other dreams , just as important and ultimately more fulfilling. I marvel at the devotion of her husband, who becomes, husband, caregiver, mother and father to the family. Highly recommend this book. You will appreciate the joy of life!

The author, chronicling her last years of battling with ALS, amazed me in how she chose to find and give the best of herself during her final days on earth. Deciding to make each moment count, she focused on her 'bucket list' of things to do, most of them centered around family and friends. I've seen her on video during her final days when she could barely utter a sound and she continued to smile, despite the situation. On the flipside, the book also reminded me that it may be a bit easier to put on a brave face when one has such a strong support system. Too many others in the world suffer on their own, with little help, and they are great role models too.

As I said in the headline my mom was diagnosed with a terminal illness, we would wind up finding out later that she was misdiagnosed, but for these few weeks when we thought we were going to lose each other our whole world crumbled. Someone suggested that I get this book for my mom so I did and she read it and said that while nothing can take away from the pain of her leaving the world so early the book did help to comfort her and provide a different view.

I normally don't read books that I might feel are "sappy" or overly sentimental. But I saw Susan on the Today Show and found her story to be interesting and her to be very real about her disease. I was a newspaper reporter at one time, and it's a go, go, go job that takes lots of energy. I understood her when she explained how hard it was to leave that thrilling world! But now I work in geriatric medicine and tend to see death quite often with the older folks. This book reminded me that there will always be an end of life, but how we accept it, face it and live until that happens is the beautiful journey we are all on. It's certainly not fair that the author contracted ALS (for some unknown reason), but she's made a real-life decision to live with it. Literally. She lives every day like we all should, except she can see the end of the road. Still she goes on, making sure all the little details are taken care of when it comes to her children, family, friendships. And she lets all the other details go (so what if the dog is eating your shoe!). I believe we are all put on this planet to learn and teach. She was put here to teach us how to accept our fate - fair or not fair - and to still take the time every day to see that others are happy and taken care of too. I bought two hard-back copies for the doctors I work for, hoping that maybe they will identify with the value of life, even though death is right in front of us.

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