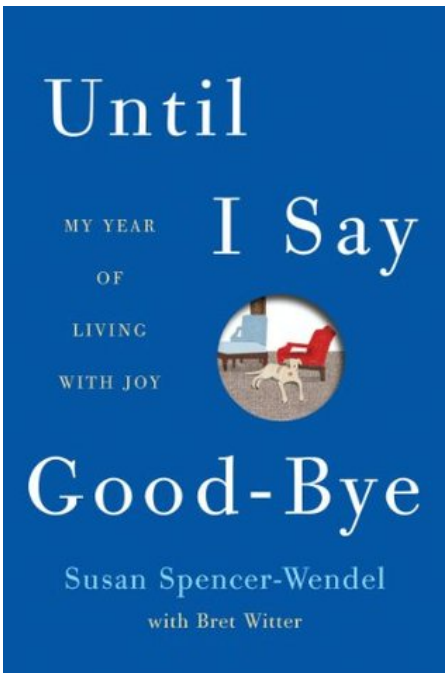

Until I Say Good-Bye: A Book About Living

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In June 2011, Susan Spencer-Wendel learned she had amyotrophic lateral sclerosis (ALS)—Lou Gehrig's disease—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 parts—how could it not be?—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 ones—a heartfelt record of their final experiences together—but an offering to all of us: a reminder that "every day is better when it is lived with joy."

Until I Say Good-Bye: A Book About Living Details

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From Reader Review Until I Say Good-Bye: A Book About Living for online ebook

Mmars says

I have been putting off writing this review because how does one criticize a book written using one finger on an iphone? Written by someone terminally ill with ALS? Someone whose positive attitude should be an inspiration to all of us. A writer - an award winning journalist? Not to worry, I'm not going to totally tear it apart. I enjoyed reading it and Spencer's honesty about and determination to cope with with its impact on her, her family, and her friends is laudable.

But here's my rub - this woman has money. Money to do whatever she wants for one year. Travel. Shop in NYC. Build a little hut near her pool in Florida. How many Americans in her position have been bankrupted by illness? And I'm not just talking about "poor" people. I'm talking about hard-working people who have worked full-time and scripmed and saved their entire lives just to see their savings vanish over unexpected and uncovered medical costs?

Plus, she has connections to get her book published by a major publisher (an imprint of Hodder & Stoughton/Hachette group). What sort of an advance did she get for that? They could at least have edited it so that there was less repetition and dropped prepositions. And there, folks, is where this book loses a star. It should be a three star book by GR standards because I recommend it the proper audience and that is a large audience. However, the editing is shoddy and her style didn't wow me, she is a journalist, not a memoirist. Sorry. I'm just being honest.

Doris Evans-McCarthy says

Yes, I know that the number of stars I gave this book is lower than the average given by other readers, but hear me out. I think Spencer-Wendel is a very brave woman for being able to still get out there and live her life despite slowly being robbed of every single thing the human body can do (except for thinking). Gradually she is being locked into an infantile, dependent body, riddled with ALS (Lou Gehrig's disease). She sets out to spend her last relatively healthy year accomplishing some things: finding out about her birth parents and taking trips to various spots around the world with family and friends.

What I wish she had done more of in this book is talk about her experience of the disease, rather than just bucking up and being brave. I think the losses she was encountering were every bit as important to the story as were the discoveries outside the disease. She was so careful to not slip into self-pity that she left out something I think is crucial to a memoir of this kind.

Still, it's a good read, filled with one woman's idea of what to do in the face of death. Not everyone approaches death the same way. Some might decide to end it all with a diagnosis like this. She chose to live through it and be there, especially for her children.

I do have to say, though, the episode of taking her 14-year-old daughter to Kleinfeld's was painful to read. Big mistake.

Karen White says

I cannot recommend this book highly enough. Reading the description may make you think: Oh, no, too depressing. But this is truly one of the most inspiring books I have read in a good while. Susan Spencer-Wendel lets us in on a year of her life, that is sadly likely to be close to the end of her time here, where she chooses time and time again to live in and with joy, despite the challenges thrown in her path. And on top of all that, she keeps a sense of humor.

I was so so so honored to have narrated this book.

Alisa Bowman says

When I picked this up, I, for some reason, anticipated a cross between Tuesdays with Morrie and Eat, Pray, Love. It's not either of those books, and perhaps that's why I found it disappointing. I expected something different--a moving tale full of deep insights about what it's like to face a premature death. While there are definitely some beautiful insights, I came away feeling as if the book was rushed, perhaps for good reason. It reads like a first draft, one that could have been smoothed and polished into a gripping, moving tale...but wasn't. The raw material is there, but it never got the editing it needs to make it shine. Due to the progression of the author's disease and possibly to the fact that she typed a lot of the book using just her thumb, much of the needed editing and rewriting never seems to have happened. So the book goes back and forth in time, which gets confusing in places. There are sections that could have had much more impact. For instance there's a scene when the author's son is caught in an elevator and she can't get out of bed to help. She's stuck in bed listening to his cries for help and must rely on others in the house to help him. It ends with her learning that he's okay, but there's no realization. She doesn't explore what that moment means--how she'll have to trust the others around her more and more to do her job as mother--and how she will come to terms with that. I came away liking the author and wanting only happiness and peace for her and her family, but I can't say I came away feeling as if my time with the book was well spent.

Luis says

"Imagine your body slowly becoming paralyzed; trapping you inside of a you that once ran, danced, and made love. Now, imagine coming to terms with your life and its ending. Susan's journey calls upon you to love with all your soul."

~ Luis Carlos Montalván, Author of the New York Times Bestseller, Until Tuesday: A Wounded Warrior and the Golden Retriever Who Saved Him

Laurie says

I read this book in several days. I did not want to put it down. It was so well written. We will all die and we

have a choice as to how we spend our final days. Susan chose to spend it in joy, but she also acknowledges her deep sadness in leaving her children and her husband too soon.

I remember when they did a fundraiser for ALS at the SF Giants AT and T Park baseball stadium and I saw several young children around 15-20 years old who had the disease but were still healthy. I could feel their pain and anguish and their parents as well. ALS is an awful progressive disease where your body dies slowly, one muscle and nerve at a time.

Susan puts a spin on it that I did not expect. She shares her anguish and that of her husband and children, but the main focus of the book is on how to live well with the time she has left.

She makes a clear decision not to spend her time in therapy and hospitals, but living life as fully as she can. I love how she explores her roots with her birth father in Cyprus and takes time to go through her photographs for her children. She creates a special Chickee hut in her backyard where she can lounge and enjoy the beauty of nature. She also takes a trip with each person she is close to--her son, daughter, husband, sister and dear friend.

Those are all things I would want to do if I knew death was near. And, of course, they are things I should do now--as soon as I can--because none of us know how long we have.

The book is a wonderful reminder to live in the moment, to have the strength to live with uncertainty and to let go of what you can no longer do. She talks, for example, of no longer being able to swim and letting it go..focusing instead on what she can do and can enjoy.

The book helps me to remember that when I get frustrated because my knee does not work as well as I would like, or I don't have as much energy as I want--to let that go and appreciate the general health that I do have--life is such a gift.

Thank you Susan for writing this book. It is a true gift to me and to the world. I feel like I really got to know you through this book and to care about you and your family. Blessings to all of you.

Bonny says

Let me start by saying that I am neither capable nor even allowed to pass judgement on such a personal memoir, thus *Until I Say Good-Bye* presents quite a paradox for me. I'm going to give my perspective without a rating. I admire Susan Spencer-Wendel for many characteristics - her ability to live with ALS unflinchingly, her humor, grace, acceptance, desire, and perseverance in writing the book. The author states, "First and foremost, I wrote the book for my family and friends to have, to jog their memories after I'm gone." In this capacity, she succeeds immensely. In the face of her rapid neuromuscular decline until she is left with only the ability to type with her right thumb on her iphone, she manages to write this book with the help of Bret Witter.

The paradox for me is that I think this book is most successful as a very personal memoir, for the author's children, family, and friends, but the publication of this book, along with a movie deal, will allow Spencer-Wendel and her family the ability to "Live with joy. And die with joy, too." This is such an intensely personal story that while I can admire the author, I don't think I can ever really understand her circumstances along with those of her family. It does serve as a reminder of how lucky most of us are, something which we will most likely not be able to acknowledge so personally until we experience our own unlucky

circumstances.

Shelly♥ says

A very moving and touching story. Susan (the author) has ALS. Even as she is writing this book, her muscles and nerves are deteriorating. Eventually she will die. But even with her right thumb the only functioning digit, she taps this story away on her iPhone. It's the story of her life, molded into the perspective of someone seeing the end come too soon. And as she accepts her diagnosis, she decides to live joyfully in spite of it all.

Have you complained about something today? Or have you rejoiced in the opportunities you've had? Sure life isn't easy, but it could be much harder. And if you read this book, it will change your whole perspective on "harder." And you will realize that you have the power to determine how you feel about anything that comes your way. YOU can make a difference.

This was a beautiful book. Susan perfectly blended the last years of her life - dealing with symptoms and finally the death sentence, with the things that had shaped her and prepared her for this time. And then she grabbed the proverbial brass ring to ride with joy to the end - painting memories for her family into the sunset of her life.

I fell in love with Susan's spirit, her sense of adventure and the love she has for everyone around her. I will recommend this book to everyone!!!!

Look for it's release in March of 2013.

Note: I received a copy of this book from the publisher. All opinions expressed are my own.

JanB says

When the author was diagnosed with ALS she decided she wouldn’t spend her remaining time going to endless doctor’s appointments in an attempt to delay the inevitable. She made a conscious choice to spend a year crossing off items on her bucket list and making memories with the special people in her life.

Susan’s book is part travel journal but along the way we get a glimpse into her family, which includes meeting her birth mother for the first time, parenting a child with Asperger's Syndrome, and getting a puppy. Most of it was typed on her iphone using only her thumb, the last digit she can still control.

Susan writes about living with joy and accepting what is, not what we would wish. “Our decision to just be. Accept. Live with joy anyhow. And die with joy, too”. Susan doesn’t shy away from the physical realities of living with ALS, and while I’m heartbroken for her and her family, mostly I am moved by Susan’s courage, strength, positive attitude and sense of humor. She has left a legacy to her children, not of how to die, but how to live with joy and gratitude.

Sachin Ganpat says

I really wanted to like this book. After all it is a true story, written by someone who is really dying. It would be cruel, and heartless, to not like this book, far more to criticise it, not so? But I didn't like it.

I was looking for a book that I could have empathised with the author. It started out great. I felt her pain. I felt her uncertainty. I felt her sorrow... then it went downhill soon after.

It started with all the jet setting, then all the demands on her family, and friends, and on her husband. No matter what, she had to get her way. She needs the ceiling painted, does she hire a painter (it's not like she doesn't have the money), no, she asks her seventy-something dad to do it for her. Constantly I didn't feel acceptance or enlightenment, instead I felt the author's utter selfishness and conceit.

I can't fathom what it would be like to be in her position, and I do admire that it did not stop her from doing anything, even writing this book. But this book is not inspirational, and I am sure many people in her position would not be able to fly all around the world, or visit the Yukon, or even get a book published.

I have no idea as to who I can recommend this book for, but if you're looking for inspiration, this is not the book to find it.

K says

An easily readable book on a tough topic.

This memoir recounts the experience of a 44-year-old woman diagnosed with ALS. Instead of giving into self-pity, Susan Spencer-Wendel makes a conscious choice to live out her remaining time with joy -- taking trips she's always wanted to take with the people she loves and forming happy memories, even as her functioning declines. Naturally, reading about Susan's deteriorating health and bleak prognosis was painful. But I feel this is an important book to read for people who, like me, need to be reminded to appreciate what they have.

The book wasn't perfect, and I considered a three-star rating at times. The narrative sagged occasionally, weighted down by details which were probably more interesting to live through than to read about -- an occupational hazard of writing and reading memoirs in general. Also, while I recognize that this surely says a lot more about me than it does about Susan, while I fully admired Susan's bravery and positive attitude, I also felt that I couldn't completely relate. Boy, would I be a wreck if this happened to me. There was some acknowledgement of Susan's considering suicide and feeling discouraged, but a lot more emphasis was placed on her positive attitude and successful insistence on restraining her urge to complain and always seeing the glass as half-full. When I read about someone who displays so much more courage than I would have, part of me is in awe and part of me feels a bit distanced, like I can't relate to someone who would have done so little griping and complaining. But again, that's me, not the book, and Susan has set a powerful example for those of us not suffering terminal illness but rather, the myriad little hassles of life.

Four stars. A quick read. An important lesson.

Susan Spencer-wendel says

I am the author. Hope you all laugh more than you cry. -- Susan

Ensiform says

The author, a journalist in Florida and mother of three, was diagnosed with ALS at 44 years old. Deciding that she had about a year of health, more or less, left, she decided to live it with joy and pack it with as much travel, family time, friends, and fun as possible. She takes her Asperger's son to swim with dolphins, has her 14-year-old daughter try on wedding dresses at Kleinfeld's (on the premise that she will not live to see the real thing), finds her roots in Cyprus, tries to see the northern lights in the Yukon, and vacations in the Bahamas. She also writes a book, of course, tapping it out with her thumb on an iPhone.

This is an extraordinary journal of positivity, adventure, hope, and love. It's absolutely tear-jerking in some places, and only a bitter curmudgeon would criticize it. So here I go. First and foremost, this is a family diary; it is a tribute to herself, for her children. I don't question in the least the need for this tribute for her family, but I'm not sure that there's a wider purpose here beyond family closure, as there was with the similar The Last Lecture. And I certainly could have been content for her family euphemism for defecation, "stink pickle," to stay in the family. There's also a disjointed chronology which means some parts get told twice; surely her co-writer could have tightened this up? Finally, this may be needlessly picky, but Spencer-Wendel seems incredibly naïve about a lot of things, which distracts from the book's main point. How can an award-winning journalist in her forties, a mother of three with a master's degree, not have ever even heard of ALS or Asperger's, much less Cyprus' Green Line? I found that very odd. Okay, heartless criticism over. Spencer-Wendel's an undeniably brave woman, and her Buddhist-like wisdom (remove needless want, and you remove pain; don't fear merely possible negative repercussions, but embrace adventure) is inspiring; I'm glad for her that she got a movie and book deal for her family's security, even if I find the book a bit too personal to be truly affecting.

Sonia Gill says

Let me be clear about this: Susan, as a person, deserves 5+ stars for being fearless (to borrow her description in the book), courageous, inspiring. Her story is incredibly sad and despite a horrific prognosis, she chose life. The book, however, is disjointed--overall, and within each chapter--and I expected a lot more from an award winning journalist. I really felt this only deserved two stars for the writing quality but gave it three since she wrote it on her phone. I feel like the wicked witch, leaving this review, for again, Susan is simply amazing! But this is a book, and phrasing, tone, and quality do matter.

Diane says

Beautifully told and such an inspiration. I would read it again to remind myself to live in the moment and cherish all that comes my way.
