

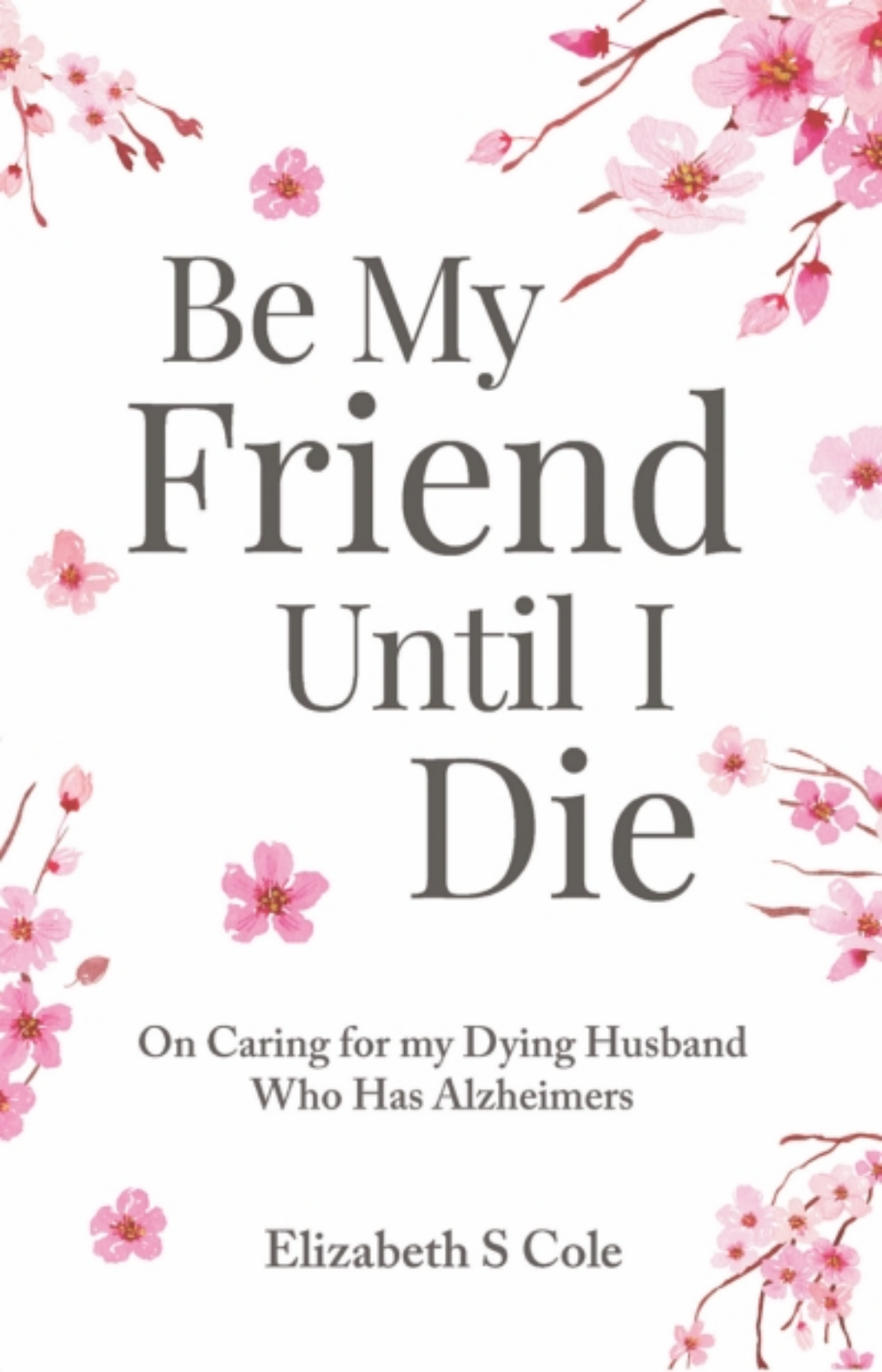
*This wise and poignant memoir offers a pragmatic glimpse into the joy, pain and humility experienced while caring for a dying loved one with Alzheimer's disease. It is the story of their love as they faced their greatest challenge together.*

**Be My Friend Until I Die:**  
**On caring for my dying husband who has Alzheimer's**  
By Elizabeth S Cole, MSW

**Order the book from the publisher Booklocker.com**

**<https://www.booklocker.com/p/books/11606.html?s=pdf>**

**or from your favorite neighborhood  
or online bookstore.**

The book cover is decorated with delicate pink cherry blossoms and branches. Some blossoms are in full bloom, while others are buds. The branches are thin and dark brown, with small green leaves interspersed among the flowers. The blossoms are scattered around the title and author's name, adding a soft, romantic feel to the design.

# Be My Friend Until I Die

On Caring for my Dying Husband  
Who Has Alzheimers

Elizabeth S Cole

Copyright © 2021 Elizabeth S Cole, MSW

ISBN: 978-1-64718-690-6

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, recording or otherwise, without the prior written permission of the author.

Published by BookLocker.com, Inc., St. Petersburg, Florida.

Printed on acid-free paper.

BookLocker.com, Inc.  
2021

First Edition

## **DISCLAIMER**

This book details the author's personal experiences as a wife caring at home for her dying husband and about how his Alzheimer's disease shaped this care. The author is not a healthcare provider.

The author and publisher are providing this book and its contents on an "as is" basis and make no representations or warranties of any kind with respect to this book or its contents. The author and publisher disclaim all such representations and warranties, including for example warranties of merchantability and healthcare for a particular purpose. In addition, the author and publisher do not represent or warrant that the information accessible via this book is accurate, complete or current.

The statements made about products and services have not been evaluated by the U.S. Food and Drug Administration. They are not intended to diagnose, treat, cure, or prevent any condition or disease. Please consult with your own physician or healthcare specialist regarding the suggestions and recommendations made in this book.

Except as specifically stated in this book, neither the author or publisher, nor any authors, contributors, or other representatives will be liable for damages arising out of or in connection with the use of this book. This is a comprehensive limitation of liability that applies to all damages of any kind, including (without limitation) compensatory; direct, indirect or consequential damages; loss of data, income or profit; loss of or damage to property and claims of third parties.

You understand that this book is not intended as a substitute for consultation with a licensed healthcare practitioner, such as your physician. Before you begin any healthcare program, or change your lifestyle in any way, you will consult your physician or other licensed healthcare practitioner to ensure that you are in good health and that the examples contained in this book will not harm you.

This book provides content related to topics physical and/or mental health issues. As such, use of this book implies your acceptance of this disclaimer.

# Table of Contents

PATIENCE.....	3
KEEPING HIS DIGNITY .....	7
IT TAKES A VILLAGE (BUT YOU MIGHT NOT ALWAYS WANT IT) .....	13
WHAT HAS HELPED? .....	17
TAKING CARE OF ME .....	27
THE LAST FEW MONTHS .....	29

## **PATIENCE**

It takes patience to take care of someone whose memory does not work and is still ambulatory. He gets himself food which sometimes winds up in his pockets and he puts things back where they don't belong. Frozen things wind up in the pantry and peanut butter in the freezer. He needs the same kind of supervision a five-year-old does. My Jack has liver cancer and receives hospice services. Three months ago he was given an undefined "not long to live, maybe six months". I am thankful he is in no pain. Jack eats very little and sleeps most of the day. He can get himself to the bathroom and back. I do not see the illness I expected to see in a man who may have only months to live.

Coping with this requires a different kind of patience. There is the familiar kind of patience used when you clean up the mess when something is broken. It takes another more difficult kind of patience to let the disease take its own course. There is no manual for how he will die. His course is his own. No doctor or hospice nurse, as skilled as they are, can draw a map for us. Accepting that this is, and will be, an uncharted journey is very hard. It is

impossible to explain this feeling to others because I don't want him to die soon. All my life the hardest thing for me to do is to cope with the unknown. I know I can handle a short race, but can I do a marathon?

Even when I think I know how to deal with some of his behavior, it changes. It helps when I learn how to deal with some things he does. It gives me confidence that if that thing comes up again, I will know how to deal with it. Jack remembers taking pills every day. When he started hospice all these drugs were stopped. Out of the blue he asked one day for his medicine. I knew I couldn't explain why he was no longer taking pills in a way that he would understand and accept. I decided to give him a vitamin pill and say this was it. I thought the vitamin might actually help since he eats so little. This satisfies him.

It doesn't pay to get too confident because before you know it, something else quite new and different comes up. My first reaction often is, "Oh my God! What do I do now?" Once over the shock and fear I try to figure it out. The first thing I try is seldom the best solution. You learn you just have to try different things. My friend Mary Lou told me a story about when her granddaughter Ava was three. When Mary Lou got frustrated trying to put together some toy she had brought, Ava said, "Ammy, you have got to learn how to



problem solve.” All caretakers are problem solvers who are constantly being tested. I am learning that I may fail again and again before I find something that works. This is such a difficult lesson for us overachievers. It is humbling.



## **KEEPING HIS DIGNITY**

Being sick is humiliating for everyone. Strangers have access to every body part and ask you to respond to embarrassing questions about bodily functions. Losing his memory has been painful for my Jack. This is a man who without a college degree holds twelve patents on manufacturing processes and products. He had so many interests. Chamber music was his favorite especially Beethoven's Late Quartets. He quoted poetry by the yard. He wrote a poem about his war experience which was published. He devoured books and loved to debate current events. Now I had to find some way to get him to wear Depends and sleep in a hospital bed. I rely on my most successful technique – I lie.

We live surrounded by woods and meadows. He loves it here. There is a bank of floor to ceiling windows in our living room overlooking our deck with flowerpots and the lawn where we have planted a tree every anniversary. I have Jack's hospital bed set up in front of the windows. He can see sky, birds, trees and flowers, and he can see who is coming up our deck to see us. He can hear his beloved music on our stereo and me puttering around in the

kitchen. I learned this from my friend Velia. When her husband John was dying she had his bed set up in the living room in the middle of everything. People came and went and their dog stayed near him. She wanted whatever life he had left to be as close to normal as possible and so did I. I like the prayer, "Let me not die while I am still alive." This is my goal for my Jack, may he live as fully as he can every day he has left and not just exist.

We were fortunate because forty years ago my plan-ahead husband had a full bathroom with a walk-in shower installed off the living room for "when we got old and couldn't do the stairs". He doesn't think he is sick and asked, "Why the bed?" We have a sofa bed facing the window where I planned to sleep. I told Jack I had a really weak knee and the doctor did not want me to go up and down the stairs. I told him I didn't want to be alone and asked him if he would stay with me. Loving husband that he is, he agreed.

Explaining all the medical people coming to our house was the first big lie. Jack's medication was provided by the Veteran's Administration. We went to one of their physicians twice a year to authorize the drugs. I told him that since he was 90 he no longer had to go to the VA. They were sending nurses to him. He asked Nurse Sue if she was being paid by the federal government. She is - Medicare.

Two years ago, he learned that his cancer was untreatable and would most likely be the cause of his death. He told the oncologist that he had been an 18-year-old Marine in the South Pacific during World War II and had survived Iwo Jima. He had seen more dead people than the doctor would in his entire career. He was philosophical. He told the doctor that when he was 18 he didn't think he would live to see 19. Every day after that was a gift. He says he has had a good life and no regrets. He accepts his illness. He has no fear of death but he wants to live. Because of his last diagnosis, nothing between us and others he loves is left unsaid. What breaks my heart is when he tells me he is getting stronger every day. I smile, nod, and bite my lip to keep from sobbing.

Jack is puzzled why people come to the house when I go out. He thinks he is not very sick and is capable of caring for himself. At 90, it is insulting to have a caretaker or minder. My brilliant mechanical engineer has never learned to deal with household electronics. I am our family's electrical engineer. When caretakers come I explain that they are here to watch the house systems, the phones, the air conditioning, the Nest, and the alarm system.

Early on in his dementia I did not handle some things very well and we both suffered. I failed to remember and use something I had learned early on in my social work professional education. In my

first year of graduate school I worked with two groups of children who were intellectually impaired. One group had mild to moderate deficits, the other's loss was profound. The group with the most suffering and anger was the mild to moderate group. They knew there was something wrong with them. They were different and were sensitive about it. They blew up at me when I offered the slightest correction. When Jack's memory was failing I would question his recollection of events if they were way off. This made him very angry. For example, he told me that early in our marriage I had moved to California and lived there seventeen years. When I protested that this never happened he got very angry at me and I at him for not accepting what was the truth. I was hurt. Was this his way to tell me that I had let him down? I would dissect his words like I was analyzing a poem for hidden meanings. This was not working for us. But the lie did. The next time he told me this I apologized to him and asked for forgiveness saying, "I was young and foolish." The issue was dropped and forgotten. What I learned is that correcting someone who has dementia is not a winning game. You may be correct but the more important question to ask yourself is, "What do I win if I win?" I now agree with everything he says except anything that would harm him or me.

Listening to what he says with love is a gift I try to give him every day. So much of what he says doesn't make much sense or it is

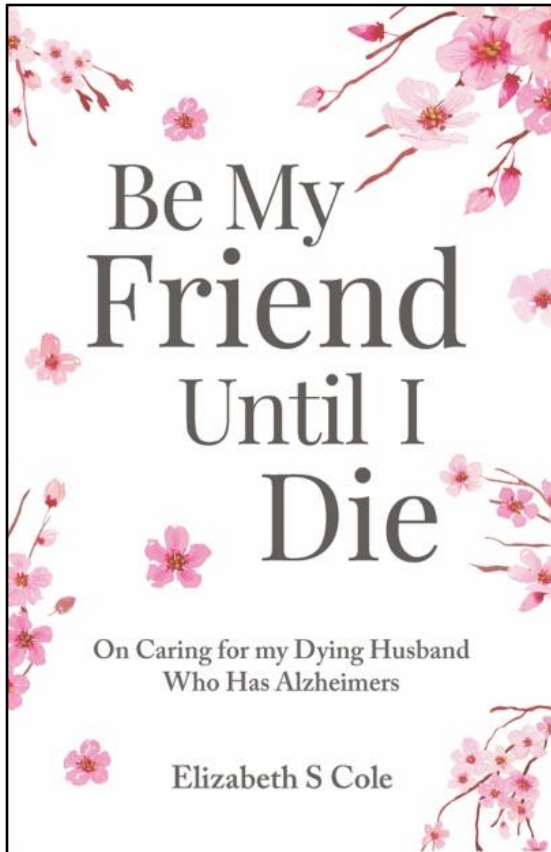
repetitive. I also learned from my challenged clients that while they may not always understand what you say to them, they frequently sense what you feel about them. This wasn't too hard for me; it was reminiscent of the way I didn't understand a word when Jack tried to explain to me what string theory was in mathematics. I didn't have to feign the love.

One of my tasks has been sparing him sorrow. Lately he has wanted to see his mother who has been long gone. He misses her and wants us to pick her up and bring her for dinner. He thinks she might be living in our barn. Early on when he asked about his mother I told him she had died. Now I know that it is not helpful. It makes him sad. I tell him she has gone to Nova Scotia to paint. He vaguely remembers her going there in the past. He also asks about his older brother, Ed. I tell Jack that Ed is in France with his French wife Gabriele. He asks me that several times a day. Jack's sister Muriel died last week. I will not tell him.

I lie a lot about money. My Jack was a child of the depression. Although his father had a job as a school teacher, sometimes the milk bill for his five children didn't get paid on time. Jack now thinks things cost the same as they did in the 30s and 40s. He is shocked when a sandwich costs \$10. I say it is for two or more. I have learned the hard way that I have to warn service people who

come to the house what to tell him their services cost. I had hired two young men to come with their chain saws to cut up some trees that had fallen in our meadow. When they came, I was taking a shower. Jack told them we would give them \$5 an hour and they left.





*This wise and poignant memoir offers a pragmatic glimpse into the joy, pain and humility experienced while caring for a dying loved one with Alzheimer's disease. It is the story of their love as they faced their greatest challenge together.*

**Be My Friend Until I Die:**  
**On caring for my dying husband who has Alzheimer's**  
By Elizabeth S Cole, MSW

**Order the book from the publisher Booklocker.com**

**<https://www.booklocker.com/p/books/11606.html?s=pdf>**

**or from your favorite neighborhood  
or online bookstore.**