

One Pedal at a Time

A Novice Caregiver and
Her Cyclist Husband
Face Their New Normal With Courage,
Tenacity and Abundant Love

CJ Golden



Copyright © 2018 CJ Golden

ISBN: 978-1-63263-988-2

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 Abuzz Press, St. Petersburg, Florida.

Library of Congress Cataloguing in Publication Data
Golden CJ

One Pedal at a Time by CJ Golden

Biography & Autobiography: Personal Memoir | Body, Mind &
Spirit | Family & Relationships

Library of Congress Control Number: 2018931791

Printed on acid-free paper.

Abuzz Press
2018

First Edition

Cover photo by Creed McPherson

Also by CJ Golden

TAO OF THE DEFIANT WOMAN

Five Brazen Ways to Accept What You Must
and Rebel Against the Rest

TAO-GIRLS RULE!

Finding Balance, Staying Confident,
Being Bold in a World of Challenges

Table of Contents

PROLOGUE	IX
INTRODUCTION	1
PART ONE: FOR BETTER OR FOR WORSE	3
CHAPTER ONE: LOVE RENEWED.....	5
CHAPTER TWO: STRONGER TOGETHER	9
CHAPTER THREE: YOU ARE A WRITER.....	15
CHAPTER FOUR: FIRE, FLOODS AND RACCOONS	19
PART TWO: OUR COURAGE IS TESTED	23
CHAPTER FIVE: THE EVENTS UNFOLD.....	25
CHAPTER SIX: MY EDUCATION IN “HOSPITAL”	33
CHAPTER SEVEN: THE HEALING HAD JUST BEGUN.....	39
CHAPTER EIGHT: CAREGIVER, SOOTHE THYSELF	45
CHAPTER NINE: THE SITUATION TURNS DIRE	49
CHAPTER TEN: THOSE HIDDEN CRACKS	63
CHAPTER ELEVEN: OUT OF THE HOSPITAL	67
CHAPTER TWELVE: MAGICAL THINKING	73
CHAPTER THIRTEEN: BEING HOME	77
CHAPTER FOURTEEN: MUCH TO BE THANKFUL FOR.....	85
PART THREE: A NEW YEAR, A NEW BEGINNING	93
CHAPTER FIFTEEN: MY LEARNING CURVE	95
CHAPTER SIXTEEN: A (SLIGHTLY) DIFFERENT JOE	105
CHAPTER SEVENTEEN: LIFE REDUX.....	115
CHAPTER EIGHTEEN: ONE PEDAL AT A TIME.....	123
RESOURCES FOR THE CAREGIVER	131
ACKNOWLEDGMENTS	137
ABOUT THE AUTHOR	139

INTRODUCTION

“From caring comes courage.”

~Lao Tzu

I sat in stunned disbelief as I heard the words, assaulting and cruel, as if passed down by a punitive judge. “We are releasing him from the hospital next week. There is no more we can do for him here; medically he is stable. We suggest you find another placement – a step-down facility. You cannot care for him at home.”

My mind reeled and my senses went into overdrive as I tried, in vain, to get an extension of at least a week.

The leukemia cells that had invaded his central nervous system – mimicking the symptoms of stroke – had rendered Joe completely, physically helpless. Yet, surely in a week, I hoped, with illogical optimism, Joe would be weaned off his feeding tube. Certainly, in the span of seven more days he would no longer need the catheter. And, most important of all, the extension of time would find him stronger; capable of transferring from his hospital bed to a wheelchair without the need of the huge machine that grabbed him, much like a fork-lift, and moved his body from one spot to another.

But, the head of the rehabilitation unit was relentless and unmoving. Joe was to be discharged and there was no debating this decision.

I did not listen to them and send him to a sub-acute facility. Against all their pressing, I chose to bring him home.

What I did not know at the time of that infamous meeting was that Dr. Schmidt was correct. An extra week in the hospital would not have made a difference. By the second week home, Joe was still hooked up to his catheter and feeding tube, still required the ridiculously, heavy machine to move him, and, while medically becoming more stable, he was still greatly physically incapacitated.

I was totally unprepared for the job of being his caregiver. I'd done it earlier the same year; that was the stroke that hospitalized him for five weeks. But, he had bounced back quickly and almost completely by the time he'd been released. My duties then as caregiver were just about nil.

This was different; so very different. And, this time I had to call upon all the resources I could muster – physically, emotionally, mentally, spiritually and financially. We were fortunate, Joe and I, to have the financial means with which to hire a private-duty nurse to help. And, we were able to arrange for the special equipment that Medicare did not cover. I will never take that for granted, and I recognize the ability to cover these special costs removed a great burden off our shoulders. **I also recognize that many others do not share these same financial advantages and, therefore, have included a resource section at the end of this book that, hopefully, will help you find the aid you need and deserve – caregivers' support groups, financial assistance agencies and other valuable and appropriate resources.*

Dispensing my duties as Joe's primary caregiver, nurse, "mother," my mind kept going to the adage that what doesn't kill you makes you stronger.

I was not sure which was going to strike first.

Chapter Four: Fire, Floods and Raccoons

Now that I was ready to celebrate my birthdays, I had decided that for my sixtieth I would join my daughter in Phoenix and, together with one of my closest friends, I'd participate in the Susan G. Komen Three Day, Sixty Mile Walk.

Logging twenty miles a day on sore and calloused feet, while helping to raise money for this very worthy cause, was one of the most exhilarating things I'd ever done. So much so that my daughter and I did it again the following year.

We were so very proud of ourselves for having logged such great distances. Until Joe raised the bar and decided he was going to ride his bicycle across the country in celebration of his upcoming sixtieth birthday.

And so, in 2007, the year before his milestone birthday, Joe, began to train by riding his cycle around town – increasing his mileage, speed and stamina as he went. For the main event, I was to be the SAG (support vehicle); we would plot a route and ride 100 miles a day. In a month, he'd be done. Not even close to realistic!

But I remained steady and ready to help him achieve this lofty goal until one day he came home and, with an apologetic face, told me he found a group he could ride with but that meant I would not be his SAG and go along.

It is hard to hold back that kind of joy, but I did; expressed that I was pleased for him, didn't let him know how unbelievably relieved I was and even tried to arrange my facial expressions into some semblance of sad/regret/disappointment.

In May 20, 2009, Joe and I drove down to Yorktown, Virginia where he was to embark on his trek to Florence, Oregon, a distance of 4,000 miles. That would be considered a daunting task for most, and

especially for Joe, who'd not cycled further than around our neighborhood prior to undertaking this trip.

One might assume that he was not ready to undertake such a ride. One would be right.

Joe learned as he cycled; he learned the perseverance needed to tackle the mountains, he learned how difficult it is to ride sixty miles or more every day; he learned the art of setting up a tent quickly in the rain; he learned to endure a very sore butt as he sat upon his saddle. But, he also learned that tenacity and inner strength goes a long way towards achieving a major goal like this.

And, he did it. From leaving Yorktown in the pouring rain, to arriving in Florence in beautiful sunshine, Joe pedaled every single inch of the way; not once getting off the bike to walk up a mountain. Three months later, I flew to Florence to witness him achieve that destination with his fellow cyclists. I grinned with great pride as he dipped his rear bicycle wheels into the ocean (when embarking on a cross country trip like this, the riders begin by dipping the front bike wheels in the ocean and end with the rear wheels in the ocean on the other shore.)

Other long-distance rides followed; in 2012, he rode the Pacific Crest Trail from the Mexican border to the Canadian border.

His last (so far) ride was another cross-country trek from San Diego to St. Augustine, FL. that began on September 14, 2015.

It was that ride that now carries more significance than I ever thought possible, for it has become the standard by which we equate Joe's subsequent recovery from his devastating illnesses of 2016.

As difficult as it is to ride one's two-wheeler for thousands of miles, it was the state of Texas that tried its darndest to stonewall the cyclists. One thousand miles – a third of the entire trip – was comprised of Texas' terrain, climate, weather and fauna. Every possible obstacle was thrown in their paths. And those thousand miles came close to succeeding in ending the trip but for the stamina, endurance and down-right stubbornness of Joe, my long-distance, cyclist husband.

One Pedal at a Time

He and the group rode through hailstorms, passed massive fires, endured torrential rain, were waylaid by the ensuing floods, cycled hundreds of miles without access to water – other than the bottles packed on their already overweight bikes - set up their tents and were plagued by raccoons and fire ants, all while dealing with the state's monstrous heat.

Yet he endured, and watching Joe ride into the final destination of St. Augustine, Florida was one of the most joyous experiences of my life.

Neither of us could have possibly imagined that a mere six months later Joe would be embroiled in another intense challenge; one that tried to take his life.

There was no intense fire, nor were there floods or raccoons.

There was, however, the stroke caused by leukemia cells attacking his central nervous system.

We referred to his time in the hospital as Texas; for as he made his way through that, he would now have to employ the same fortitude and strength of character to get through the new challenge.