

Me? A Caregiver?



A MEMOIR BY
MARY BETH HARRIS

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Illustrations by Janet Harris Bowe

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Some names and identifying details have been changed to protect the privacy of individuals.

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For Mama

When you run into a friend whose loved one recently passed on, let them do the talking. This is not an appropriate moment to share your despondent experiences. This time is about them. Not you. Don't talk. Listen. Please remember this piece of advice.

ACKNOWLEDGMENTS

This book never would have been launched if certain friends and acquaintances hadn't offered to take my hand for a brief moment, walked with me and lent me their ear. Shortly after the conception, when the manuscript was quite rough and dreadful there were those who saw potential and encouraged me to continue. Marlene Martin, Nicki McMahon and Gita Caplan politely listened to re-write after re-write (even when I bored myself) and they urged me to keep going.

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My captivating friend, mentor, author and founder of Nightwriters writing seminars, Phyllis Theroux, reluctantly offered, "I will read only twenty pages and I will be brutal." Then two days later at her book signing at Harrison Library in Carmel, she spotted me and said, "I read the whole manuscript and liked it." Thank you Phyllis for the productive and pleasurable week I spent working with you in your charming writer's cottage in Ashland, VA.

My talented sister, Janet Harris Bowe showed her love and support by enthusiastically listening to each chapter then created the most amusing but candid illustrations. If you don't know me or didn't know Mama, I can assure you

that Janet captured not only our physical likeness but she understood the spirit of our journey.

Shary Farr, Founder of Partners for Transitions, was unyielding that I finish this book. I can't imagine how Mama's life or my life during this time would have been without Shary and her never-ending love. Her kindness and compassion is unmeasured. Her knowledge and skills are invaluable. How do I thank an angel in street clothes?

My sister Susan's boundless support and persistence that I finish this book was the driving force to the end. She sat with me for hours listening to chapter after chapter then she stayed by my side as we proofread together. I'm not so certain that this book would have ever gone to print without her picking me up when I faltered and loving me so unconditionally from the moment I entered this world. My love and appreciation for my big sister is infinite and our bond is divine.

I am indebted to the extraordinary Carmel Foundation who delivered delicious dinners for a minimal fee when I lived with Mama. The Carmel Foundation then generously lent us a wheelchair, commode, and shower chair when Mama lived with me. The Carmel Foundation is a treasured asset to our community.

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INTRODUCTION



It was a huge production. A hospital bed and an airflow mattress were ordered. Mama's twenty prescriptions and eleven bottles of vitamins had been updated and transferred to a closer pharmacy. Caregivers lined up to be interviewed, hired, presented with a detailed job description, and trained. Visiting nurses and physical therapists prescribed by Dr. Hart needed directions.

I purchased diapers, wipes, under pads, tissues, and latex gloves discounted in mass quantities online. They were stacked all over the large room. I'd ordered an electric lift chair off the Internet but it was the wrong size, wrong color, and poorly constructed. It sat in its box labeled TO BE RETURNED, and on top of it sat new sippy cups, a huge bottle of baby powder, a tube of A & D diaper rash ointment, and a clock.

The temperature was high into the 90s as I sat on

a borrowed commode from our wonderful Carmel Foundation. A hospital tray (also borrowed) served as my desk, and it was piled high with papers and three days of unopened mail. A new mega-size box of Tylenol and a tall glass of iced tea sat at the edge. Sweat poured continuously down my brow and fogged the readers perched on the end of my nose. The oscillating fan didn't do much but send papers flying to the floor.

I glanced at the clock and noticed that the hospital bed should have been delivered over an hour ago. I would call them next, but first some of Mama's money needed to be transferred from one account to another and a prayer needed to be said that the money would hold out. As I waited for Mr. Logan (Mama's finance guy) to answer, I searched through the mess of papers for the Home Hospital Care number. I spotted it as Mr. Logan answered. He had handled Mama's finances for years, so the transaction went much smoother than tracking down the overdue hospital bed. I then dialed the Home Hospital Care number and the phone just rang and rang. I was about to hang up when someone answered.

"Hello, Home Hospital Care, Andy speaking. May I help you?"

"Hi, this is Beth Harris, is..." I scrambled for the contact's name on the small business card "...Margaret there?"

"Sorry she stepped out for lunch. Is there something I can help you with?"

"Well, I ordered a hospital bed which was to be delivered

today between 10:00 am and noon. It is now after 1:00, the bed's not here, and I am concerned."

"Let me see if I can help you with this. Can I put you on hold?"

Oh God! I remembered previously being put on hold at Home Hospital Care for what seemed like hours. First deafening music, then an announcer who sounded like a game show host. I wasn't at all up for that, but I had stuck a fresh estrogen patch on that morning and felt polite. "Sure, I'll wait."

Then I heard it. The loud ghastly music, then that voice. "HOME HOSPITAL CARE. WHEN YOU BRING A LOVED ONE HOME, BE PREPARED. WE SUPPLY OXYGEN, HOSPITAL BEDS..."

Luckily I heard Andy's voice back on the line. "Uh, ma'am? When was that order called in?"

I rolled my eyes towards heaven and thought, *Oh hell, here we go again. Stay calm.* "It was faxed to your office Tuesday for delivery today between 10:00 am and noon. I am concerned because I am picking up my disabled mother from the nursing home around 3:00 and I need to make up the bed. I need it here ASAP."

I heard Andy riffling through papers and I sensed his nervous energy. I picked up the cold glass of iced tea and held it against my sweaty forehead, then closed my eyes and took a deep breath.

"Uh, ma'am? Who was the doctor that prescribed the bed?"

I moved the glass to my chest. "Dr. Hart ordered the

bed on Tuesday. His nurse faxed the order to you around 10:00 that morning. Is there a problem?"

"I hope not ma'am. I..."

I was getting agitated every time I heard "ma'am." I had to interrupt. "Excuse me, Andy?" Another deep breath and I said to myself, *Remain calm, remain calm, and remain calm.* I exhaled. "Could you please not call me ma'am? My name is Beth." I wasn't at all surprised by his next response.

"Oh I am so sorry ma'am. I mean Beth. Could you tell me the patient's name please?"

I repeated my mantra to myself. *God get me through this. God get me through this. God get me through this...* "Her name is Ellen Harris; and to recap, Dr. Hart's nurse faxed the order Tuesday around 10:00 a.m. When will Margaret be back from lunch?"

There was dead silence like poor Andy was afraid to speak. "She won't be back until around 2:00. It's her birthday so her co-workers took her out to lunch."

I dropped my head and moved the iced tea behind my neck. *God get me through this, God get me through this, God get me through this...*

"Look, Andy. I need this bed delivered ASAP. Is it possible that the delivery guy might have a cell phone? Could we call him?" My head had been pounding for a couple of hours. I wasn't sure if it was the heat or the stress of making these arrangements, but suddenly my eyes were fixated on the box of Tylenol sitting at the edge of my tray.

"Oh, that's a good idea. Let me see if I can find the number." Andy sounded a bit relieved. Again I heard him

riffling through papers; then he picked up the phone. “Uh, Beth? I need to put you on hold.”

Before I could object, “HOME HOSPITAL CARE. WHEN YOU BRING A LOVED ONE HOME BE PREPARED. WE SUPPLY OXYGEN, HOSPITAL BEDS, COMMUNES...”

Frantically and with the help of my teeth, I tore open the gigantic box of Tylenol. I jabbed a pencil through the foil and made a big hole, then popped two pills into my mouth, took a sip of the iced tea, threw my head back and swallowed. I needed to go downstairs for more ice, but I heard Andy.

“Uh, Beth? Good news. I found the delivery guy’s number.”

I sighed a huge sigh. “Oh thank God. What did he say? Where is he?”

“Oh, I didn’t call him yet.”

My blood simmered but I made the effort to be nice. “Welllllll Andy, perhaps you could give him a call or give me the number and I will call him.”

“I’ll call him now. Please ho...” This time he didn’t even get the entire last word out before he pushed that damn hold button.

“HOME HOSPITAL CARE. WHEN YOU BRING A LOVED ONE HOME BE PREPARED. WE SUPPLY...”

The game-show voice went on and on and I knew this would take a while, so I went downstairs to the kitchen for more ice. The freezer was cool and I wanted to stay there all day but I had to get back to my commode in case

Andy had more questions. I filled the glass, popped a cube in my mouth, rubbed one on my forehead and one between my drenched breasts, then headed back upstairs. I let my cat Toes in on the way. I picked up the phone just as Andy answered.

“Uh, Beth?”

“Yes Andy. Good news?”

“Did you order a commode with that hospital bed?” Oh My God!

“What? Are you freakin’ kidding me? No I didn’t order a commode. In fact I’m sitting on a commode, Andy! Just the bed and air flow mattress.” I inhaled. *Deep breaths, deep breaths.* “What did the delivery guy say?”

“I didn’t get a chance to talk to him because he’s on his break and he turns his cell phone off while he eats his lunch. I left him a message to call as soon as possible.”

Toes jumped up on one end of the tray and slid right off the other end, taking the opened bottle of Tylenol and remaining papers with him. Pills scattered everywhere. Toes was in a playful mood and I was not. He jumped back up and stuck his muzzle in my glass of iced tea, but when the fan oscillated in his direction he hissed at it and jumped down. I reached for a large box of Depends and hurriedly tried to open it with one hand but I stopped dead when I heard Andy ask, “What is the address on this order?”

“Is this some sort of joke? I can’t believe this! The address is 3 Dear Meadow Lane.” I struggled to open up the large box of adult diapers. “I know you are trying your best, Andy, but that hospital bed has to be here within an hour and you can’t find the paperwork!” I continued the fight

with the diaper box and finally it ripped open crudely and about ten diapers flew out. I picked one up. “Does Margaret have a cell phone? Do you have her number?”

Andy was quick to answer. “Yes she does, but we have strict orders to only use it in emergencies.”

“WELL WHAT THE HELL DO YOU THINK THIS IS, ANDY??? CALL HER NOW!” I unfolded a diaper, held it over the floor and poured some cold iced tea and a couple of ice cubes into it. Then I wrapped it around my neck and secured it with the sticky tabs. It was all I could think of to cool down my body and my anger.

“Okay I’ll call her right now. Hold on...”

“No please don’t put me on...” Too late.

“HOME HOSPITAL CARE. WHEN YOU BRING A LOVED...” *God get me through this. God get me through this.*

Toes had discovered the ninety-eight pills that spilled and was batting them all over the hardwood floor. I wasn’t sure which sound was more annoying, the game-show voice or the pills rolling from one end of the room to the other.

“Uh, Beth?”

“Yes? You better have good news because I’m getting pretty pissed off here and you don’t want to piss off a menopausal woman in the middle of a heat wave, Andy. Do you know what I mean?”

I heard a very timid voice. “Uh, Beth?”

“Like the guy says, I AM bringing a loved one home and trying to be prepared, but you are making it really difficult, Andy, really difficult.”

“Uh, Beth?”

“Do I have to come over and pick the damn bed up myself?”

“Beth?”

“What Andy, what?”

“The delivery guy called and said he was running late and that he’ll be there any minute.”

Just then I heard the doorbell and yelled, “Who is it?”

“Home Hospital Care.”

I held my hand over the phone and yelled downstairs. “Do you have a hospital bed?”

“Yes ma’am.”

“Come upstairs.”

I spoke gently to Andy.

“He’s here. I’m sorry I was so cranky. I know you did your best and I appreciate it. You’ve been very patient. Thank you, Andy.”

“Sorry for the delay, Beth.”

“Bye Andy.”

A voice yelled up to me.

“Ma’am did you order a commode with this?”

I put my head face down on the tray, and tea from my diapered neck dripped over the few remaining papers. *God get me through this. God get me through this, God get me through this...*

To purchase a copy of *Me? A Caregiver?* please visit meacaregiver.com

Ellen Harris, an independent woman, a passionate artist and a devoted mother vowed never to be a burden to her children. Her youngest daughter, Mary Beth Harris, an independent, free spirit, was finally landing her dream job in Hollywood. It never occurred to her that she would become her mother's caregiver. But when rheumatoid arthritis severely crippled Ellen's hands and feet, mother and daughter came together and now, instead of ordering expensive champagne and limousines, Mary Beth was ordering a hospital bed and airflow mattress.

There were times when Ellen's pain was so excruciating that she wanted to die and times when sleep deprivation and caregivers drove Mary Beth almost to the point of insanity. But through profound love and the ability to find humor they embraced the joy of each other's company, understood the value of their relationship and honored the precious time they shared together.

“You will love Beth Harris, you will love her independent mother, and you will love *Me? A Caregiver?* which is poignant, funny, and serious all at the same time. Every mother should pray to have such a steadfast, resourceful, hilarious daughter who loves her as much as Beth Harris loved hers.”

Phyllis Theroux, author of *The Journal Keeper*

“What a gift this book is. Beth teaches us the challenging and creative aspects of being a caregiver. We learn to stretch, to find answers in all situations, to find miracles unexpectedly and most importantly, to laugh. Not only will I be a better caregiver for having read this wonderful book, but in the many aspects of being there for those I care about. I have learned new ways to be of LOVE.”

Shary Farr, Founder of Partners for Transitions

