

*#1 Bestseller*

**DAVE NASSANEY**

# **It's Your Life, Too!**

*How to Survive & Thrive  
As a Caregiver*



*"Dave is a True Caregiving Expert..."*  
*—Dean Cain, Actor & Guest Host of NBC's TODAY SHOW*

Published by  
Hybrid Global Publishing  
301 E 57th Street, 4th fl  
New York, NY 10022

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Manufactured in the United States of America, or in the United Kingdom when distributed elsewhere.

Nassaney, David

It's my Life, Too! Reclaim Your Caregiver Sanity by Learning When to Say "Yes" and  
When to Say "No"

LCCN: 2017951465

ISBN:

Paperback: 978-1-938015-77-9

eBook: 978-1-938015-78-6

Cover design by: Cynthia Lay  
Interior design: Claudia Volkman  
Editing by: Claudia Volkman  
Photo credits: David Nassaney

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# CHAPTER 1

## THE TWO MOST IMPORTANT WORDS YOU'LL USE AS A CAREGIVER

ARE YOU A caregiver? Welcome to the club. We all have our story of how we got here and how we are doing so far. Some of you are not doing very well. Some of you are at your wits end. And some of you are ready to throw in the towel. You'll want to keep reading. I believe I can help. Let me begin by sharing some background of how I got here.

It was early on a Sunday morning in 1996. I awoke from a deep sleep to find that my wife, Charlene, was not in our bed. The clock showed 6:28 a.m. It was unlike Charlene to be up so early. I called out her name, but she did not respond. *Perhaps she's in the bathroom*, I thought to myself. *Is she not feeling well? Did her three-day headache return?*

I called out to her again, still with no response. I searched the house and heard the television in the family room, with what sounded like an old Shirley Temple movie. This didn't make sense. She wasn't a television watcher. And if she did see a show now and then, she was definitely not an early riser. Something was terribly wrong.

I followed the sounds of the TV and found her on the couch. She didn't look up. I asked if she was OK, and she mumbled that her headache was throbbing and that the pain circled her head like a crown. I asked if she would like me to massage her forehead as I had done a day earlier to give her some relief. She answered yes.

I knelt in front of her and slowly massaged above her eyes. I saw her face, yet I could not adjust my mind to what was in front of me. It took me a moment or two to recognize that her face, the precious face of the person I have loved for so many years, was distorted. Her body slumped. I asked her to say something—anything. This time her mouth moved, but no words and no sounds reached my ears, as if a mute button had been pushed.

I was not well informed about strokes back on that fateful Sunday morning in 1996, but I somehow knew she was having a stroke and that I needed to dial 9-1-1 as fast as my body could make it to the phone. To my relief, the paramedics arrived quickly, and they confirmed to me that Charlene was indeed suffering from a stroke. The tantamount concern was for Charlene's life itself, which required getting her to the hospital as quickly as possible. The paramedics knew exactly how to handle her medical crisis. Their competence helped me cope with the emotional and mental chaos that overtook me at that moment.

Unfortunately, it wasn't until later on that I realized my confidence was poorly placed. There is only a three-hour window to address the symptoms of a stroke before brain damage occurs. The paramedics recommended we go to the closer and smaller hospital to get her help more quickly. Unfortunately, the facility was not as well-equipped to handle her stroke as the larger medical center just ten minutes farther down the road—to which she was eventually transferred. Due to that decision which delayed her proper care, I absolutely believe that Charlene lost her speech and became permanently paralyzed on her right side. Life is a series of decisions, and I shall regret this one as long as we both shall live.

I didn't understand at the time the full extent of what was happening, but from that morning on, our lives have never been the same. Charlene suffered a permanent disability, and I instantly became her caregiver. I had no idea how to take care of the woman I loved in this way, a woman who had been vibrant, competent, and very independent. It was extremely difficult for both of us, in different ways, to create a new way of living and relating to one another.

I do not know what event catapulted you into your current role as caregiver, but most likely someone you love suffered an accident, illness, or other life-altering experience. The good news is that they survived. The stressful reality is that now they rely on you more than ever. Perhaps you're a parent of a child who was born handicapped or has become disabled and now requires more attention than expected. Or your partner or spouse may be facing permanent or long-term limitations, no longer able to care for themselves as in the past. As the baby boomer generation ages, more adult children are caring for their aging parents while at the same time still raising their own families.

Regardless of the specifics that have put you in this place, you and I have something very significant in common. We both love people who need us, and we are committed to caring for them. This book will teach you that the well-being of the care-receiver depends on your well-being. To be competent caregivers, *we must find a new way to live our own lives* while we take care of someone we dearly love.

If you ever sat by a loved one's bed and wondered how you would be able to handle this new, overwhelming responsibility, then you're reading the right book. It can feel like you're all alone, and there's no one out there to help or support you. But the fact is that you're not alone. I want you to know that I've sat where you're sitting right now. I've felt the feelings that are pressing down on you. And I've got a very important message—you can *more than* survive this situation. You can actually live out your new role with confidence.

Your life has been radically changed. I won't minimize it, but your life has not come to an end either. You can still have a wonderful, satisfying future in spite of, or even because of, your loved one's dependency on you. I know this to be true because it happened to me. I've learned how to deal with tragedy and difficulty and have not merely “survived”—! am living a wonderful life.

I'm going to show you how to avoid the common mistakes many long-term caregivers make that set them up for needless stress and burnout. You'll learn how to take great care of yourself while providing top quality care for your loved one. I will explain how I became a long-term caregiver. You may have thought that you had nothing in common with anyone. Not true. Honestly, I suspect you'll find that you and I have a great deal in common.

## **Two Important Words**

The two most important words you'll use as a caregiver are “Yes” and “No.”

You might be very good at saying “Yes,” or maybe you didn't have the choice to say “No.” A lot of people, especially caregivers, want to help others. Either way, it's also common for caregivers to take on much more than they can handle, and this can lead to some negative results:

- Feeling guilty for letting other people down
- Resentful about having too much to do for others
- Feeling obligated to sacrifice their own needs

When our loved ones were in the throes of their trauma, focusing on their needs was the appropriate response. I was by Charlene's side when she was in the hospital, and fighting for her life. I suspect when illness struck or the accident occurred or the tragedy hit, you put your life on hold and did everything you could to help your loved one. Nights in the hospital. Days off work. Questions asked. Records kept. You gave your total attention to the crisis as adrenaline pulsed through your veins and your mind tried to remain singularly focused.

It's common for caregivers to live on adrenaline, late night cups of coffee and heightened emotions day after day after day. In fact, it can become a lifestyle if we're not careful. When I was basically living at the hospital for a week or two, I didn't realize that I hadn't been home to change clothes, shower, eat or even sleep until a family member brought it to my attention. It was very easy and natural for me to just stay there by Charlene's side, visit with the friends and family who stopped by her room, snack on the food trays they would bring her that she didn't eat, and take cat naps with her in her bed while the night nurse looked the other way. I was depriving myself of rest, nourishment, exercise and personal hygiene.

When my daughter finally *forced* me to go home, I fell into my bed and slept for fifteen hours. When I got up, I took a hot bath and ate some wonderful leftovers that my wife had frozen. It felt so good to have my needs met again. I finally realized that I was killing myself with neglect. My wife never even missed me while I was recovering that day, and no one made me feel guilty for taking a break. It was an eye-opener for me that life goes on, and I *must* put my needs first. Sure, it was hard in the beginning, but when I saw the consequences of neglecting my health, and I realized that I would *never* let my loved ones do that, I made it my policy from that point on that I would go home every night from the hospital. That policy continues at home today, taking frequent breaks from my duties as a caregiver.

Strong emotions such as fear and anger are meant for short-term situations. But they will destroy us, physically, emotionally, and spiritually,

if we say “Yes” to them on a long-term basis. I remember a time when I first realized that my beautiful, articulate wife might never be able to speak in sentences again. Discovering that we could no longer have deep conversations, walks on the beach, or walk *anywhere*, I was afraid, and I was angry. But it didn’t take more than two days before I felt this pain in my stomach. I felt like I was giving myself an ulcer. Can you imagine if I allowed myself to go on for months or years carrying around that fear and anger? Many caregivers often suffer from colitis and stomach bleeds. I am so glad that I quickly learned the benefits of saying “No” to such strong emotions as fear and anger.

You may not be as dependent upon others to meet your needs, but your needs are as valid as those of your loved one. It is equally important to have your needs met as it is for the person who is in need of special care. Making priorities, balancing your commitments, assessing and deciding the best course of action for your care-receiver, and learning new skills will all make you a better caregiver. Just because you can walk better than a two-year-old doesn’t mean that you can walk a tightrope without practice. Anytime you’re trying a new thing...it will feel unfamiliar to you, even uncomfortable or painful at first.

I am an entrepreneur. I run a business. I hire and fire people. I balance books, buy and sell inventory and pay the bills. I didn’t think I had what it took to be a caregiver back then. I was really good at making money and balancing budgets. But to take care of my wife’s stroke symptoms of speech impairment and paralysis, be her voice, her legs, her hands? Not me. I didn’t believe I could do it at the time. I was scared. I was angry at myself for not demanding that the paramedics take her to the big medical center, instead of the closer, smaller “rinky-dink” private hospital. That decision caused her to not get the proper medications that would have dissolved her blood clot and prevented brain damage. But what choice did I have at the time? I didn’t know anything about strokes. I had to forgive myself and move on with what happened. I took it one day at a time. The days rolled into weeks, the weeks into months, months into years, and eventually into a couple of decades. I ultimately learned what to do and how to do it by trial and error. Fortunately for me (and my wife), it was sooner rather than later. Now you can benefit from all my mistakes.

For example, I have never really dressed a woman before—you know, underwear, bras, support stockings, and those shoes and buttons! Oh, how I

hate those shoes! They never go on easily, just like Cinderella's stepsister's foot that wouldn't fit into the glass slipper. And those buttons, all sizes and shapes! The smaller the button, the more impossible it is to button it through that tiny button hole. I know it sounds silly, but I believe that's why God made zippers and slippers that have no buckles . . . just for caregivers.

### **Batteries and Boundaries**

If you are miserable, you won't be able to provide hope and comfort to your loved one. If you feel exhausted, like a dying battery, you will be unable to accurately recognize their needs or properly care for them. With the best of intentions, you may undermine your health and well-being and become ill yourself. There are times when you must acknowledge that your life is important and say "No."

Saying "No" can be hard because most of us have been taught to feel guilty about it. We feel selfish. If you've been brought up in a Christian home, you have probably been taught that to sacrifice yourself for others is a spiritual virtue. Jesus sacrificed Himself for us, so we are to sacrifice ourselves for others, right?

I believe that we are to follow Christ's example and serve each other. As caregivers, service is the primary thing we do every day. But there is nothing noble about burning yourself out. Jesus often went away from the crowds to replenish Himself. He would habitually go away by Himself into the mountains to meditate and pray to His heavenly Father. He was under so much stress while speaking to the large crowds. He had to debate the religious leaders, avoid His enemies from stoning Him, raise the dead, heal the sick, walk on water during a severe storm at sea, take frequent naps in the back of the boat, feed the multitudes with only five fish and two loaves of bread, be the peacekeeper to His disciple's frequent arguments amongst each other, keep them safe, and so on. He definitely knew how to squeeze in His "me" time. Remember, the Bible says that He was 100 percent man and 100 percent God, so His body was subject to the same limitations as ours (hunger, thirst, pain, temptations, stress, etc.).

He also maintained important relationships with His friends who supported and cared for Him. That's right; Jesus had a support group . . . actually many. His heavenly Father was His best support. He could tell Him anything (good venting time). His disciples were a support for Him as well,

helping Him do the hard work of His ministry. His mother was a huge emotional support, especially during His last days on earth. He had other close friends like Mary, Martha, and their brother, Lazarus, whom Jesus wept over when he died and then raised from the dead because He loved him so much.

The concept of believing that I was not alone, that God was there with me, was invaluable. I remember feeling like that famous picture of the two footprints in the sand, where there were only one set of footprints during the most difficult of times. That was because God was carrying me (as well as my wife) in His arms. I felt like I was floating on air, as though my feet never touched the ground during those really tough couple of years in the beginning of her stroke.

For example, I remember in the hospital being visited by dozens and dozens of loving people offering their support and prayers for what happened. Singers we know came into the hospital room to sing to my wife and I beautiful uplifting songs that were such a blessing. Weeks and weeks went by that God would inspire certain people to help us and offer their prayers of encouragement each and every day. It just felt so good, and I remember thanking God for sending these wonderful people to comfort us. It was like I was floating on air, and the nasty circumstances below us were not even close enough to touch us.

While we strive to become more like Christ, we must not start to believe that we are limitless and all-powerful like God is. It's easy to forget that we are limited human beings who deserve to live rich, fulfilling, and even fun lives.

Saying "No" sets a boundary that protects you from excessive stress and self-destruction. A lot of people who need you to take care of them do not like to be told "No." This may be especially true of your dependent loved one. But there are times to say "No," and this book equips you to know when and shows you how to say "No."

Don't misunderstand me—I'm not saying that you should abandon your loved one or leave them uncared for. Not at all. I want to show you how to say "Yes" to both yourself and to the person you love in such a way that you can be the caregiver you want to be.

## **Let's Talk About You**

At the end of each chapter, I will invite you to focus solely on yourself. You can write your responses in this book, or use a journal to record your thoughts, feelings, and decisions. You spend a great deal of your time and energy attending to the needs of others. This will be a time just for you. You deserve and need time to reflect on yourself. I know this is so because I am a caregiver myself. Let's talk about you.

- Did you have the luxury of planning ahead? Or were you surprised by a tragedy? Preparing for the expected changes will equip you to better deal with this change in your life. What do you expect will happen in the next days, weeks, months?
- How are you handling this “New Normal?”
- Do you ever feel resentment towards your care-receiver? If so, why?
- Do you ever feel like giving up?
- What is your greatest joy of caregiving?

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