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Learn and Live

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Tuckered Out?

Tips for maximizing your energy

The Girdle

A frustrating day in the life of one caregiver

Brushstroke

A portrait of a looming stroke

Life at the Curb

Ticket to Ride (and Park)

Making the World a Better Place

Inspired caregivers improve the lives of others

Dr. Beth Frates,
 Physician and Family Caregiver

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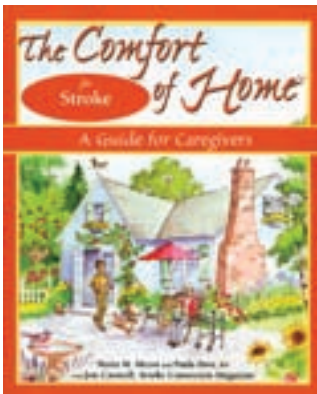
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“Caregivers of stroke survivors are overnight thrown into a full-time job they did not ask for, were not trained for and that has no end date. It is very important that caregivers know from the beginning that they have to find ways to take care of themselves. This self-care is not an indulgence; it is a necessity, and they must make it happen.”

Spreading the Word About the Comfort of Home

Most family caregivers of stroke survivors experience enough to write a book, but who has the time? After a seven-year stint helping her husband coordinate the care of his father, who experienced a series of debilitating strokes, Maria Meyer did exactly that — wrote a book and founded a publishing company that specializes in resources for caregivers and trainers. *The Comfort of Home™: An Illustrated Step-by-Step Guide for Caregivers* has been used by caregivers for more than a decade and is now in its third edition. This year she published a new edition targeted to caregivers of stroke survivors: *The Comfort of Home™ for Stroke: A Guide for Caregivers*.



“After watching my husband’s family negotiate their father’s care, I felt you get more training and information when you buy cosmetics than when you bring a stroke survivor home from the hospital,” said Maria, a mother of four and grandmother of four.

While she was not the primary caregiver, Maria observed her husband struggle with her father-in-law’s care every day, and she became familiar with the complexity of caring for a person

who is incapacitated. “For seven years my husband and his family dealt with the challenges of caring for their father at home,” Maria said. “When we were finally able to get a team of qualified, reliable and trained professional caregivers together, things changed: His health and outlook on life both improved. We brought him home from the nursing facility with the expectation of his living another month, and he lived for seven more years at home. A good team of caregivers was able to eliminate the frequent visits to the hospital for constant bouts of pneumonia. It allowed us to give him the best possible quality of life.”

There were frightening and unhappy experiences as well. “Our most difficult times were dealing with inadequately trained professional caregivers. We once discovered, for example, that he had been given a near-toxic amount of concentrated medicine because the home health aide was not shaking his medicine bottle prior to dispensing the medication. The medication had separated in the bottle and floated to the top, so he was being given a dose at 100 percent concentration, without dilution. We only discovered this by observing him growing increasingly listless over several weeks. We ordered a blood test and discovered the problem.”



Caregiver and author Maria Meyer

Maria’s experience showed her that caregiving is not only complicated, but has serious consequences. She could see how doing it well made a huge difference. “Our primary job was to put together and supervise a team of caregivers for a stroke survivor who needed constant care,” Maria said. “In hindsight, I wish I had better understood how difficult the role of caregiving for stroke really is. Knowing this now, I would look for more skills, or at least be sure resources were available to train and support the caregiver aides in that role. Sometimes we mistakenly think this is a simple job, just a matter of hiring an aide to help someone with activities of daily living. It is actually much more complicated than that. Try transferring a 180-pound person from a bed to wheelchair, or understanding that a grimace on the face

of a person who can't speak actually tells you he is having a painful foot cramp, which you can't observe because the foot is covered with a sock and shoe!"

Maria put her experience and that of a team of professionals into a 400-page manuscript that took three years to complete. "I decided I needed to find a way to publish what I had observed to help others in similar circumstances understand what they were taking on," said Maria. "There were very few resources for a family that needed simple tools to deal with stroke — or caregiving for any condition." The guide is an illustrated compendium of basic knowledge necessary to take care of a family member at home — from transfers to end-of-life issues to medication planning to tips for preventing caregiver burnout.

But having a manuscript and publishing a book are two different things. "I only had a vague plan for what to do next," said Maria. "Even though my co-author, Paula Derr, was a nurse, I knew most publishers would want to see a track record. I didn't have one, nor was there any guide for family caregivers like this one on the market. My expertise was in understanding what caregivers need to know — and especially how they need the information presented so it is most useful to them. I also wanted to control the user-friendly design of the book. So, I decided to start a publishing company, CareTrust Publications, with the publication of the first edition of *The Comfort of Home*™ in 1998. Its mission is serving caregivers with high-quality, user-friendly information for those who face an illness or the responsibilities of caring for family, friends or clients."

Since then Maria has sold tens of thousands of books in *The Comfort of Home*™ series, which includes specialty guides for caregivers of multiple sclerosis and Parkinson's disease. Soon there will be special editions for Alzheimer's as well as chronic lung disease and liver disease. The series, now viewed as the "bible" for caregivers, also won the Benjamin Franklin Award in the health category.

"Caregivers of stroke survivors are overnight thrown into a full-time job they did not ask for, were not trained for and that has no end date," Maria said. "It is very important that caregivers know from the beginning that they have to find ways to take care of themselves. This self-care is not an indulgence, it is a necessity, and they must make it happen.

"November is National Family Caregivers Month. Caregivers should acknowledge that this is a special role beyond being a spouse or adult child and seek out support from others in the same situation by attending support group meetings and get the basic skills and information to protect their own physical and mental health while they provide care for their loved ones. I hope *The Comfort of Home*™ guides will give caregivers confidence and take the fear out of home care." (continued)

The Comfort of Home™ caregiver guides are available wherever books are sold or at www.comfortofhome.com.

Giving Caregivers a Voice

For Suzanne Mintz, life changed when her husband Steven developed a tingling sensation in both legs that wouldn't go away. A visit to a neurologist brought weeks of tests — and scary uncertainty — that ended with a frightening diagnosis: multiple sclerosis (MS). It was 1974, and she was only 28 years old.

MS is an incurable, degenerative neurological disorder that can cause changes in sensation, visual problems, muscle weakness, depression, difficulties with coordination and speech, severe fatigue, cognitive impairment, problems with balance, overheating and pain. In severe cases it causes impaired mobility and disability.

As her husband's condition deteriorated, Suzanne found out what it meant to vow "in sickness and in health." After many years of being isolated in her caregiving role, she connected with another caregiver, Cindy Fowler, and the women discovered that sharing experiences and emotions was satisfying and helpful. "But as family caregivers, we wanted someone to reach out to us, to tell us where to find helpful information and advice, emotional support and real hands-on assistance when we needed it," Suzanne said.

In 1993 Suzanne and Cindy co-founded National Family Caregivers Alliance (NFCA) to help caregivers connect and give them a voice in politics and the media. "NFCA was created to educate, support, empower and speak up for America's family caregivers so that all caregiving families can have a better quality of life," Suzanne said. In addition to being her husband's caregiver, as NFCA president she educates policy makers and the public about the important —

and sometimes forgotten — role of family caregivers.

The NFCA recently released *Love, Honor & Value* (see p. 29), the Mintz's story and a resource on caregiving. For more information on the NFCA, visit www.thefamilycaregiver.org.

< Suzanne and Steven Mintz

