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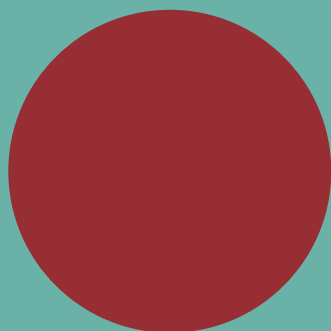
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Sign up now!

THE COVER:
MARSHALL MANSION
Photograph by Green Street Studio



Berenice and Herb Kleiman discussing their book at Joseph-Beth Booksellers, Legacy Village. PHOTOS BY MARC GOLUB.



Lives Reshaped

Berenice and Herb Kleiman's book, *One Stroke, Two Survivors*, is a strangely compelling and powerful love story.

BY BETH FRIEDMAN-ROMELL

In their 43 years of marriage, Herb and Berenice Kleiman have pursued their passions together, becoming parents, successful business partners, world travelers, and avid theatergoers. Five years ago, they were thrust into two new and unwelcome roles – patient and caregiver. On July 14, 2001, Herb suffered a massive stroke that turned their lives upside down.

From the moment Herb's symptoms began during their yearly Canadian theater trip to the Shaw Festival, the Kleimans faced choices. Should they trust the small, local hospital, or race back home to the advanced facilities of The Cleveland Clinic? Should they assume the life-threatening risks of an aggressive stent procedure? Should Berenice micro-manage all aspects of Herb's care, or take a social worker's advice and "go with the flow"?

Herb survived with his mental faculties intact, but suffered significant physical impairment. More choices. Could Berenice shoulder the exhausting 24/7 responsibility for Herb's care at home, or would he be better off in a nursing home? Should they modify their existing home, or try to find a more accommodating living space? Should a wife relentlessly push an uncooperative husband to adhere to a strict diet and tough rehab goals, or should she respect his desire simply to be left alone, and risk losing all progress gained?

One Stroke, Two Survivors: The Incredible Journey of Berenice and Herb Kleiman (Cleveland Clinic Press, April 2006) is a candid and intimate account of the Kleimans' struggle to reshape their lives in the stroke's aftermath. For Berenice, what began as therapeutic venting, undertaken to kill time while waiting for innumerable doctors' appointments, evolved into a book-length caregiver's manual, packed with helpful suggestions, resources, psychological insights, and moral support.

"We wanted to leave a trail for others," Berenice explains. She says that most chronic care books are either written from the third person perspective of doctors or clinicians, or are mini-treatises on caregiver philosophy. "We wanted to talk about how to get through the day, the little as well as the big issues."

The book also provides a how-to approach to wading through oceans of medical red tape. Berenice wants to empower families to demand that the medical community treat the patient as a whole being, not "in parts."

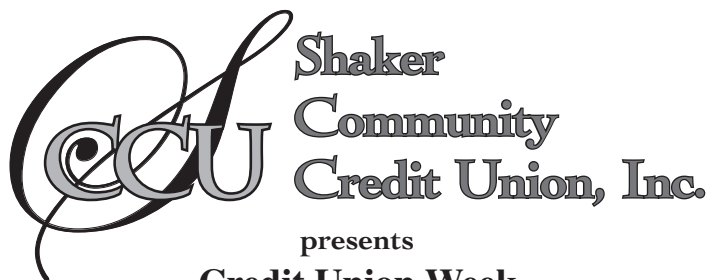
But for Herb, "It's a love story. No one else would be willing to tolerate the chores that she has done.

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Lives Reshaped

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Five years after, she still believes in me, that I can function as an almost-complete human being."

The book seems an unlikely candidate for the romance shelf, with such chapter titles as "Caregiver's Anger," "Toiletting Nightmares," and "When You Think You've Reached the Lowest Level of Hell, Watch Out for the Next Descent." But love story it is, and a strangely compelling one, even to those outside the presumed target audience. The characters' strong, often dissenting voices boldly reveal their personalities, warts and all.

Berenice's experience in education, law, and marketing (not to mention a healthy dose of chutzpah) have made her a savvy and tenacious advocate for her husband. In the face of medical indifference, sometimes incompetence, her demands have been unrelenting. When Herb's phone and emergency call button were carelessly placed on his paralyzed right side at Metro Health's Center for Rehabilitation, Berenice crawled under the bed to rearrange the cords. She waged a one-woman battle to ensure he received diabetic meals, with all packaging pre-opened. She is a maniacal record-keeper, juggling medications, appointments, and therapies.

But nothing prepared the Kleimans for the grueling new routine awaiting them at home. Berenice was not trained in the essentials of injecting, dressing, showering, and exercising Herb before his discharge from the hospital.

The Kleimans' youngest child, Steve, was their savior. He temporarily left his work in California to help his parents adapt their home and their lives to the situation. As Herb writes, "Steve was very talented with coming up with non-standard solutions to our problems.... He was unconventional yet highly effective."

Steve rearranged the house for wheelchair accessibility, devised garage access, and built specialized exercise equipment for his father. More important, he took charge of Herb's physical therapy regimen, a literal and figurative sore point between Herb and Berenice to this day.

Do's and Don'ts to Help Stroke Patients and Caregivers

1. DO LISTEN patiently in a one-on-one discussion, and permit the stroke survivor to express a full opinion. DON'T interrupt to express your own thoughts until he/she has finished.
2. DO allow room and time for the stroke survivor to enter the conversation, particularly in a larger group where discussion is rapidly exchanged.
3. DO encourage caregivers to provide both visiting opportunity and ground rules. Friends too often draw away from stroke survivors because they feel awkward or at a loss to know how to communicate under adverse conditions.
4. DO reach out and hold the door open for people in walkers and wheelchairs. Doors are often heavy and awkward.
5. DO look directly at people in wheelchairs, smile and offer a greeting. The ill and disabled are people and deserve respect.
6. DO consider respite for the caregiver. An offer for an hour or two of friend sitting can be much appreciated. But be sure you understand the ground rules.
7. DO provide a listening ear for caregivers. They also experience periods of loneliness.
8. DON'T offer unsolicited advice.
9. DON'T discuss your illnesses and family problems with people overwhelmed by their own. It won't make them feel better.
10. DON'T walk away from ill and disabled friends because contact makes YOU feel badly. Think how their lives have changed.

—Berenice and Herb Kleiman, with Beth Friedman-Romell

Herb was never someone who enjoyed working out. Nevertheless, his youngest child pushed him twice a day to lift legs, roll hips, and painstakingly take steps with a walker.

“We were told the recovery curve was six to nine months from the stroke,” Steve explains. “It was absolutely easier for me to push him than [for] Mom. I was the bad cop. I wouldn't let him brush me off.”

While Herb still adheres to a physical therapy program, Berenice writes that it is less rigorous than when Steve was in charge. That's understandable, since Herb now experiences intense facial pain when he exercises.

Food is a second source of friction between Berenice and Herb. Berenice's chapter on “Food-Smart Recovery” recounts her efforts to control Herb's diabetes and reduce risk of another stroke. She has, in fact, eliminated Herb's need for injected insulin. Herb views Berenice's approach as “zealotry”; she has recently learned to bend a little once in a while. (On the day of this writer's visit, Berenice served Herb not one, but two slices of very delicious cake.)

The food battle encapsulates the central tension of the book – Berenice's desire to maximize recovery vs. Herb's desire to be

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Lives Reshaped

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left alone. On one hand, her efforts, along with the support of a cadre of therapists, have helped Herb regain his ability to speak, expand the use of his left hand (he was right-handed), and take some steps with support. On the other hand, Herb struggles to cope with the “quantum” changes to his life, and often wonders if the struggle is worth the cost – financially, emotionally, and physically.



Herb at home on his treadmill.

Before Herb's stroke, the Kleimans poured their energy into the marketing and communications consulting firm they formed in 1987. Client meetings would occur around their handsome dining room table in their Mercer-area home, with a lunch break for corned-beef sandwiches from Corky's. After work, they might take in a show, or attend one of the local college courses they loved to enroll in together. Or perhaps Berenice might work on her latest play script while Herb tended the yard, made home repairs, or polished off one of his frequent speeches or articles. Maybe they'd take a long drive – with Herb behind the wheel.

Today, “It's BORING!” exclaims Herb, in no uncertain terms. The routine of exercise-dressing-grooming-doctor appointments-occasional trip to Costco is

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multitasking for an engineer with advanced degrees in business and economics. While Herb can use his computer, he finds his interest in writing waxes and wanes dramatically. And conversations are difficult unless the room is quiet and the listener is sensitive to Herb's slower speech pattern.

If Herb's nemesis is boredom, Berenice's is stress. She is well aware that caregivers suffer up to 25 percent higher mortality than the general population. Stress-busters include solo vacations, visits from their kids and grandkids, small breaks to take an exercise class or have dinner with a friend, and, when all else fails, massive doses of chocolate.

She has learned "I no longer have to do everything for Herb. It is a disservice to both the caregiver and stroke survivor when we negate our own existence."

And so the Kleimans have achieved a small measure of their former lives, having resumed their enrollment in college classes and their beloved theater trips to Niagara-on-the-Lake. In fact, the book provides a very useful chapter on traveling with disabilities.

Berenice is also grateful for the support of her neighbors and friends. Since Steve and his sisters, Kathryn and Miriam, live out of state, the Kleimans do not have a family support system in town. But neighbors and their children have reached out, caring for pets and shoveling the snow. In addition, several part-time professional caregivers have eased the burden.

The family is also fortunate in that they are financially secure. Berenice estimates they spent \$40,000-\$50,000 in the first year alone on medication, clothing, and home adaptation. Medicare and AARP supplemental insurance covered their hospital, rehab, and therapy expenses, but prescriptions and home health aides are an ongoing drain on the nest egg of two people who never planned to retire in the first place.

"If there's one lesson you can get from reading this book, it can happen to anyone, at any age," warns Herb. "We thought we had planned, but we didn't. The change is a quantum jump."



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