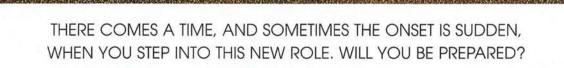
TRANSFORMATION

From Child to Parent, Taking Care of Mom and Dad



BY LINDA MEIERHOFFER

inni Simpson was isolated. None of her friends understood why she no longer had time for an evening out with the girls or a long chat on the phone. Ginni was busy outfitting a bathroom with shower grab bars and an elevated toilet seat, as well as rearranging furniture in a guest bedroom. With every change to the home where she had

lived a contented life, her frustration and sadness grew. Ginni's mom, widowed when Ginni was only 12—and a healthy, competent, take-charge working woman most of her life—was now whittled away by chronic obstructive pulmonary disease (COPD) and had nearly died from a massive blood clot. Now she was coming to live with Ginni.

Overnight, Ginni, a Palm Desert resident, became one of the nearly 45 million caregivers over the age of 18 in the U.S. who provide unpaid care to adult family members or friends. Her story is not at all uncommon: AARP profiles the "typical" caregiver as a 46-year-old female with some college education who works and spends more than 20 hours a week caring for her mother. It was a month before Ginni's 50th birthday that her uncomplicated life took a radical turn with her mother's arrival. "I was busy 24/7 running a nonprofit agency when she came," Ginni says. "I fell into the child's role of wanting to make my mother happy and was frustrated when nothing I did seemed good enough. Mom was scared and depressed, but displayed those feelings by being dissatisfied and critical of everything. Our roles eventually reversed as she became sicker, and I became the mother and she the child; it was up to me to keep her alive."

The good news for all the Ginnis out there, who are suddenly thrust into the parent role for their own parents, is that help is available, both locally and nationally. The experts say the biggest mistake we make in caring for our aging parents is thinking that we can fix everything. "You have to let go of the feeling that you can do it all. Determine what you can reasonably do—and what you have to stop trying to do," says Jeanne Ruud, geriatric care manager for LivHome, a Palm Desert agency that provides non-medical at-home services that allow seniors to live in their own homes as long as possible. "Our caregivers provide help with bathing, dressing, toileting, transferring, ambulating and feeding," says Ruud. "We can also provide supervision, companionship, medication reminders, light housework and laundry, meal preparation, transportation and errands."

As a care manager, Ruud is the point of contact for the client and the family—and, with a master's degree in gerontology, she's qualified to assess and recommend a personalized plan of care to the families of her patients, which can be especially helpful for families who live at a distance. She knows that scenario, since her own parents are in their 90s, living with assisted care in Florida. "I fly there every three months and spend a few days," Ruud says. "I meet with their doctors, visit the facility administrator, keep up with how they view my folks and let them know if I have any concerns. I also invite my parents' friends to join us for a meal, which keeps me connected to their social life outside the facility. None of us plan to take care of our parents—it can be easier to look the other way and hope that things will be

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all right. But I believe in thinking ahead and preparing yourself and your parents for what might come."

Joyce White, a social worker and clinical liaison with Manor Care, a skilled nursing and rehabilitation facility in Palm Desert, echoes Ruud's sentiment, but gives this advice: "The biggest mistake that adult children make when caring for their parents is not taking the time to take care of themselves."

LEAVING THE FAMILY HOME

How does a liberal-thinking, gay man care for a failing parent who is alcoholic, homophobic, anti-Semitic, racist and ultra conservative? Bill (not his real name) knows the answer firsthand.

"My parents could no longer take care of themselves and the four-level home in New York they'd lived in for 40 years," says Bill, a retired partner in an entertainment company, who lives in Palm Springs. "But Dad's line was, 'I'm gonna die in this house.""

It's no wonder that Bill and his brother had been estranged from their father, and by default, their passive mother, for most of their adult lives. "When I called Dad to tell him I'd been quoted on the front page of the Wall Street Journal, he said, 'Why would they do that? You don't know anything about business," Bill says.

In spite of the troubled family dynamics, the siblings stuck together. Just as Jeanne Ruud advises, they made a care plan

LET AARP HELP

Help for caregivers is as close as your local bookstore or the tap of a computer key. AARP recently issued a revised and updated version of its book "Caring for Your Parents, The Complete Family Guide—Practical Advice You Can Trust From the Experts at AARP." The authors start with guidance on how to approach the "new touchy subject" of the need for elder care. They walk readers through the healthcare maze of Medicare coverage, address various living arrangements, note multiple resources in every chapter and they include worksheets to start your own family assessment. Need to take away 90-year-old Dad's car keys? They help you with the reality check of doing just that.

Care manager Jeanne Ruud also offers this tip: "With severe dementia or Alzheimer's, allowing the person to keep a key chain with the trunk key on it will often satisfy the need to hold keys or jingle them in their pocket, which may be a lifelong habit," she says.

Is Mom's forgetfulness Alzheimer's or something less serious? The AARP authors list the steps taken by geriatric specialists, neurologists or psychiatrists to obtain an Alzheimer's diagnosis, as well as the changes one can expect with mild, moderate or severe stages of the disease. Finally, the book also provides compassionate words to help us handle hospice care and end-of-life issues. after their dad suffered a stroke and decided to move their parents into an assisted living facility in Palm Springs.

"My father knew every bond he ever bought and its maturity date, but he no longer remembered how to get from his bedroom to his bathroom, a few steps away," Bill says. "We were dealing with a proud, successful, in-control man who no longer had control of his bowels."

Bill managed their care and visited them regularly. "The best information came from my friends locally who had dealt with similar situations. I talked to everybody I knew to get referrals for doctors and nursing care. I found out which facilities specialized in what type of care."

The plan the brothers devised had several key components that can be useful to others in similar situations: the parents' medical records were transferred from New York to their new doctors prior to their arrival. Appointments were scheduled within 10 days of their move here with these new physicians. The same type of bathroom towels, specific kitchen items and their parents' favorite foods were duplicated in the new apartment. Bill worked with his father and a financial adviser his dad approved of to oversee the parents' financial affairs, giving Bill the responsibility for the day-to-day management. Finally, the brothers hired a lawyer who would represent their parents' interests when it came to new wills and trusts, thus removing themselves from the equation.

A PLACE OF PEACE

In Ginni's case, she knew what she needed to do for her mother—she is "Dr. Ginni," a psychologist who helps people cope with illness, death and bereavement in her practice. So, Ginni worked through her anger at herself and her circumstances by following her own advice: She told people what she was going through, found others in the same circumstances and joined a support group that led her to valuable resources here in the valley (see sidebar).

"I was worn down emotionally knowing that my mother was dying and there was nothing I could do to change that," Ginni says. "But my professional training taught me to exercise, eat well, laugh, avoid alcohol, to journal my feelings and find things to be grateful for."

Finally, Ginni and her mother came to a place of what she calls pure love in the months before her mom's death. "I realized after she arrived here that I needed to give her more, not fewer, choices, because so much of her power had already been taken away," Ginni says. "Our relationship was not always pretty on the outside, but we had the same sense of humor. It was that and the love we shared that deepened our connection in the last days of her life. You can't get there without traveling some tough roads together."

Bill also knows about rough roads. When asked how he, a gay man with a Jewish partner, took care of his homophobic, anti-Semitic father, Bill says simply, "I did it for me."

Bill says both he and his parents changed after he took over their care. "The nine months Dad lived after coming here was a healing time, and he was grateful for what I did for him. I knew for the first time in my life that he loved me," Bill says. "After he was gone, Mom lived a couple more years to be almost 91."

Dr. Ginni, too, now smiles easily when she speaks lovingly of her mom and quotes a Japanese haiku to help explain the unexpected gifts that come with this difficult role of parenting our parents: "Since my house burned down I now own a better view of the rising sun."



1. LOCAL RESOURCES

ALZHEIMER'S ASSOCIATION Provides education, support and advocacy, including a 24/7 helpline, 1-800-272-3900; 760-328-6767; alz.org/californiasouthland.

BRAILLE INSTITUTE Services for the blind and partially sighted; 760-321-1111.

DESERT SAMARITANS FOR THE ELDERLY

Provides grocery delivery, referral services, transportation, substance abuse, gambling treatment programs; 760-837-9066, dsft.org.

LIVHOME At-home services for seniors; 760-568-2937.

MANOR CARE Skilled nursing, cardiac and orthopedic rehabilitation, pain man-

agement, IV therapy, wound care and hospice services; 760-568-5096.

ODYSSEY HEALTHCARE OF PALM SPRINGS

Hospice care, including a new 11th Hour Vigil Program to ensure that no patient dies alone; 760-674-1723.

SENIOR LIVING OPTIONS OF THE DESERT

Free referral service to help find assisted care; 760-218-5309; seniorlivingoptionsoft-hedesert.com.

2. REGIONAL RESOURCES

MEDI-CAL CONSULTING SERVICES, INC.

Call for free phone consultation to determine eligibility for Medi-Cal benefits; 1-877-633-4435; medihelper.com.

- continued on page 36

RIVERSIDE COUNTY OFFICE ON AGING Provides coordination and advocacy for seniors and adults with disabilities; offers contracted services such as meal delivery, in-home supportive services, legal services, escorted trans portation, health insurance counseling, adult day care, caregiver programs; 800-510-2020; rcaging.org or riverside.networkofcare.org.

VETERAN'S ADMINISTRATION Information on CA Veterans' Homes that provide rehabilitation and residential care; cdva.ca.gov.

3. NATIONAL RESOURCES

AARP The Web site provides information on public benefits, prescription assistance, respite care, advanced directives and more; aarp.org.

BOOK: "CARING FOR YOUR PARENTS: THE COMPLETE FAMILY GUIDE" by Hugh Delehanty and Elinor Ginzler; save 35 percent off the \$12.95 list price; borders.com.

Go to aarp.org/caregiving and click on "Housing Options" to locate your state's ombudsman to investigate and resolve a conflict with a nursing home or to calculate the cost of long-term care options in your state.

AARP recently appointed a new Caregiving Ambassador, author Gail Sheehy, who describes the nine "turnings," or phases, of caregiving; go to aarp.org/caregiving for more information: Shock & Mobilization; The New Normal; Boomerang; Playing God; I Can't Do This Anymore; Circle of Care; Coming Back; The Long Goodbye; Afterlife of the Caregiver

ELDERCARE LOCATOR Links those who need assistance with local/state agencies that serve older adults and their caregivers; eldercare.gov.

FAMILY CAREGIVER ALLIANCE Offers state-by-state resources; caregiver.org.

HICAP Volunteers who do one-on-one counseling and education on Medicare; 800-434-0222.

NATIONAL ACADEMY OF ELDER LAW ATTORNEYS, INC. To locate an attorney who specializes in elder law; 703-942-5711; naela.org.

NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS Provides referrals to local geriatric care managers; 520-881-8008; caremanager.org.

NATIONAL FAMILY CAREGIVERS ASSOCIATION

Provides tips and tools for caregivers; thefamilycaregiver.org.

SOCIAL SECURITY ADMINISTRATION Invaluable information on Medicare, Social Security, disability, benefit planning and application; 800-772-1213; socialsecurity.gov.