Caring for Yourself as a Caregiver

Dr. Bert Hayslip Jr.
UNT Psychology Department
940-565-2675

I The demands and rewards of caring for someone are unique and ongoing.

Health-related caregiving is stressful and its impact on your physical and mental health should not be underestimated.

Relationship with the person you are caring for-
What is the quality of that relationship? What is the extent to which each person can openly communicate his/her wants and needs - physical and emotional?

Interpersonal relationships - friends, family, health professionals, neighbors. Are you isolated? Do you feel comfortable asking for help when you need it? Can you depend on others to give you the help you need? Is that help given freely?

Intrapsychic aspects - satisfaction, burden, depression, anger, guilt, feeling trapped, isolated, frustrated, or dependent, grief - Your own as well as those of the person you are caring for. Did you willingly do this or were you asked to do it? Has how you define yourself changed? How do you react to this change?

II An important first step is accurately assessing what these demands are and their likely impact on you.

Your own health: diet, physical exercise, sleep

Assessing how much stress you are feeling and developing ways of coping with this stress. You may underestimate this - be honest, know your limits, be willing to ask for help, find someone to talk to, seek out information, do not suppress your emotions, resist the tendency to label some emotions as bad while others are good.

Look for the good things in being a caregiver - what is it that you find satisfying or meaningful?

Set meaningful goals for yourself - those that you can achieve and that will improve matters for you and hopefully, for the person you are caring for.

III Find a help source - your convoy of support.

Is there someone you can call whenever you are feeling sad, depressed, angry, guilty, or when you are ill?

When you ask for help, be specific (what you need done, when, how often?).
A trusted friend, an organization that pertains to your loved one's illness
Schedule time for yourself on a daily basis, have a set time to talk to this special person
If possible, do something that you enjoy daily either alone/with someone else

Develop you own network of support- your church, friends, neighbors, family members, professionals, a support group.

IV  Develop **coping skills** to deal with the stress you are experiencing

Assess when you need help and what kind of help you need- draw up a daily routine and analyze it in this light.

Are there caregiving skills that you need? How do you acquire them?

What are your physical and emotional limits? How do you feel when you exceed those limits?
Are you able to be honest with yourself in terms of what you are feeling and experiencing?

**Coping is an active, purposeful process**- What are your short term and long term goals?

**What is your particular style of coping?**

- **Appraisal focused** (using logic and mental preparation, reframing or redefining, social comparison, denying or minimizing stress)

- **Problem focused** (seeking information and support, taking action, identifying new rewards)

- **Emotion focused** (recognizing and regulating one's emotions, being able to express one's feelings, using jokes and humor, being able to accept emotionally certain aspects of the situation)

Some styles work in some situations and not in others. Coping styles often need to shift as your caregiving situation changes.

V  Assess whether what you have tried is working or not and be willing to make adjustments.

Am I actually doing what I planned to do? (Under stress we often fall back into previously learned patterns of behaving and feeling)

Should I change how I am reacting? Behaving? Feeling? Communicating?
Do I need more help? New skills? More information?

Am I taking on too much responsibility?

Try to identify something positive that has come of your caregiving:

- Have you acquired a new skill?
- Have you improved your time management?
- Do you have more help in meeting your caregiving responsibilities?
- Has your health improved?
- Has your mood improved?
- Are you more optimistic about the future?

*Focus on what you can change (your reaction to the challenges of caregiving), and accept the things you cannot change.*

*Look to your strengths, not your weaknesses!*

*Ask for help when you need it?*

*Be realistic, yet optimistic!*
The Givers

Tens of millions of people tend to a loved one on a full- or part-time basis, often putting their own life on hold. Now researchers are finding ways to help them care for others without losing themselves.

By Francine Russo

An explosion in Afghanistan nearly took Luis Alvarado's life—and forever changed that of his mother, Sonia, who is a pastor. Although their faith was tested, the experience taught the entire family both how to give and to receive care.
On November 14, 2011, Sonia Alvarado got a 5 A.M. call from the U.S. Army. Her son, Luis, had been injured by an improvised explosive device near Kandahar, Afghanistan. Sonia and her husband, Julio, both Methodist pastors, immediately flew to Germany, where their 24-year-old son lay in a hospital in a coma, tubes crisscrossing in and out of his body. The doctors told the parents to say good-bye; Luis was showing minimal brain activity. “You don’t know how stubborn my son is,” Sonia told them.

She and Julio sat beside Luis, talking unceasingly to him. Finally, they saw him shed tears. “Keep fighting,” his mother begged, “and we will fight with you.” Thinking back on that day, she says: “We made the decision right there that we will always be taking care of him.”

Across the country, nearly one in five adults—about 43.5 million Americans—have stepped up to that kind of responsibility, providing care to loved ones who are sick, frail or disabled, according to a joint report from the AARP and the National Alliance for Caregiving. The vast majority (85 percent) are tending a relative: a parent or parent-in-law in nearly half of cases, a spouse or partner for another 12 percent, and the rest a mix of uncles, aunts, grandparents and others.

It is hard, relentless work and unpaid, although the economic value is huge—estimated at $470 billion in 2013.

### FAST FACTS

**CAREGIVING: LIGHTENING THE LOAD**

1. There are an estimated 43.5 million unpaid caregivers in the U.S. Most are tending a relative, and nearly a quarter report that their health has suffered under the strain.

2. Scientists have found that culture, gender and relationship dynamics can help explain why some people fare better than others when caring for someone in need.

3. Respite programs, counselors, peer-support groups and interventions can all help caregivers manage the challenges of their role.

As one might expect, those who log long hours are especially likely to experience emotional and physical stress, negative health effects and financial strain. Compared with the general population, they are more apt to describe their health as “fair” or “poor,” and nearly a quarter say that caregiving has led to deteriorating health.

As the population ages and caregivers’ numbers mount ever higher, the emotional, physical and financial costs to individuals and society are ballooning. In 1993, under President Bill Clinton, the U.S. Congress passed the Family and Medical Leave Act, which offers eligible workers some relief in the form of protected leave from work to care for a family member. In recent years more than half of states have approved AARP-developed legislation that requires hospitals to provide training in essential medical tasks for those caring for a relative newly released from a hospital. Nevertheless, the U.S. continues to lag behind many European and some Asian countries when it comes to support for caregivers.

It is not as if we do not know how to help. For decades—as longevity and the demand for caregiving have skyrocketed—social scientists have been unraveling the question of why some people fare well as caregivers whereas others struggle. In the process they have identified specific strategies that can help caretakers manage the burdens and maximize the rewards of their role.

These scientists recognize that caregiver well-being depends on far more than meeting practical, medical and financial needs. Family caregiving is a profound and deeply personal experience. It touches on our mortality and vulnerability, who we are as humans, as sons and daughters, husbands, wives, fathers and mothers. It asks us to find meaning in loss and satisfaction in what many would see as drudgery or endless self-sacrifice. Fundamentally, how we think about the role of caregiving plays a powerful part in whether we buckle under the strain of that position or derive a sense of purpose and fulfillment.

### Gender, Culture, Community

People can think of tendencies to a loved one as a trial or a blessing. In practice, it is a combination of both—and many different factors can tip the scales. Steven H. Zarit, a pioneering gerontologist and distinguished professor emeritus at Pennsylvania State University, is among the most devoted to this puzzle. He co-created the Zarit Burden Interview, now an internationally used tool in caregiving, to assess its emotional, physical and social impact on individuals. According to Zarit, the perception of burden is subjective and depends more on the individual’s beliefs, relationships and culture than on the weight of day-to-day duties. “Some people caring for those with many dis-
Luis, who uses facial expressions and his hands to communicate, is aided by his entire family: (from far left) parents Sonia and Julio Alvarado; sister Mariana Stovall and her children Meelo, Amaya and Alejandra.

ruptive problems feel little burden. Others feel overwhelmed,” he says.

The relationship between “care partners,” the current term for caregiver and care recipient, matters a great deal, as does the quality of that relationship: loving, hostile or ambivalent. Greater emotional closeness between spouse/spouse or child/parent partners, for example, often benefits the care recipient. But a 2012 study of dementia caregivers by Utah State University gerontologist Elizabeth B. Fauth and her colleagues found that for the caregiver, the experience was mixed. According to Fauth, it combined positive experiences with an increasing sense of loss, yearning and, for some, depression.

In a 2013 study, New York psychotherapist Judy R. Strauss reported a difference between caregivers who were sons and daughters versus those who were children-in-law (primarily women). The adult children suffered poorer mental health and family strain, whereas as sons and daughters by marriage reported less family strain and more support from their spouse. This pattern may reflect a number of factors. People may offer more praise and support to children-in-law while taking a biological child’s caregiving for granted; kids may feel more pressured to tend to their own parents than someone else’s; and finally, it may be less emotionally draining and painful to watch an in-law’s deterioration than a parent’s.

Gender differences hint at similar issues. Women caregivers, as a group, have been found over and over to fare worse than men—and wives worst of all. In a 2014 study of 533 caregivers reported in the Journal of Family Nursing, for example, the researchers documented that men generally feel less burden than women. On the whole, people see caregiving as a woman’s duty. Therefore, females tending to a loved one are conforming to expectations, but males are acting “against type” and may receive more appreciation. Other studies have found the belief that caregiving is women’s work contributes to female reluctance to use care services, so when they do enlist outside help, they feel less control and satisfaction than men in the same circumstances. Men are therefore better at asking for help and can receive support without feeling they have failed or been “displaced” by paid service providers such as adult day care workers or home health aides.

Finally, culture and ethnicity play a role. Several studies have confirmed Peggy Dilworth-Anderson’s 2004 finding

Caregiving is hard, relentless work and unpaid—yet the economic value is estimated at more than $470 billion annually.
that, as a group, African-Americans caring for loved ones with dementia have a more positive experience than whites do, reporting less depression, stress and strain. Certain cultural values, she found, foster greater resilience and “active” coping styles. (People who actively cope tackle challenges head-on rather than avoiding them.) A 2015 study by Johns Hopkins University gerontologist David Roth found that Hispanics also experienced more of the positive side of caregiving than whites. “It may be because of their stronger family connections,” says Roth, which result in more social support.

Many lessons can be drawn from such studies of group differences. Women, for example, may be taught to take a cue from men and relinquish the belief that they are the “default” care figure—and instead see their role as a choice and one for which they should seek support. Research on cultural differences suggests that all caregivers—whatever their race or ethnicity—would benefit from greater social support at the community level. These elements influence the meaning caregivers assign their role—a worthwhile, even ennobling endeavor or a thankless chore thrust on them by circumstances. Research has shown, Zarit says, that if people feel they are getting something positive out of the experience—pleasant moments together, a sense that their task is valued—they feel less stress.

The Best Case in a Worst-Case Scenario

When Luis Alvarado was transferred to San Antonio to care for his son 24/7. His sister, Mariana Stovall, and her husband and daughter joined them two years later. The entire family’s faith was sorely tested. “We went through the process of grief,” Sonia says, “being angry with God, the army, the government, everyone. Then we reached acceptance.” She let go of other dreams and ambitions without regrets. “To care for our son is our life now,” she says. “We don’t know how long we’ll have him with us. We all feel so good to be able to do this.”

Friends and members of their close-knit church community lend a hand, bringing food and stepping in when Luis’s immediate family gets sick. Throughout her life Sonia believed that people had a duty to serve others, but she had always been the giver. Her friends and congregants persuaded her to receive, explaining that it was good for them to give. “Now I welcome help,” she says.

The Alvarado family was especially well positioned to succeed as caregivers. As Latinos and Methodists, their culture and faith gave their sacrifices meaning. They felt they had the necessary strength and competence to learn and perform the required nursing tasks at a high level. And they were a close and highly functional family before the tragedy hit them.

They also demonstrate a quartet of factors proven to improve the odds of coping well as caregivers. In 1990 the late sociologist Leonard Pearlman identified three key psychological elements of caregiving: mastery (that is, a sense of control over our lives), social support and coping strategies. Scientists have recently added a fourth: strategies that directly reduce the caregiver’s physical stress levels. In practice, there is a dynamic interplay among these factors. Improve a caregiver’s ability to manage difficult symptoms, and you improve the person’s sense of mastery. Foster the caregiver’s ability to care for himself or herself, and you reduce stress levels and bolster the capacity to care well, perhaps more lovingly or, at least, more patiently.

Strategies for Coping

Care partners know each other far better than a doctor and patient. Yet a caregiver often lacks the knowledge that is needed to handle frightening or irritating symptoms—let alone maintain some sense of mastery when a condition worsens. Dementia caregivers, for instance, often have to confront a loved one’s agitation, sleeplessness, wandering and incontinence.

Solutions are invariably tailored to specific illnesses, but many strategies are adaptable across diseases. “One key for caregivers,” Roth says, “is not to take the behaviors personally.” A wife, for example, whose spouse has dementia might learn to see her husband’s tirade not as a sign of disrespect but an indication that he is frustrated with his lost capacity to do routine tasks. Roth has shown that it is possible to teach this kind of reappraisal.

In a 2004 study, Roth and his colleagues assigned 406 caregivers of a spouse with Alzheimer’s disease to receive either standard care or a counseling and support program aimed at reducing negative reactions to behavior problems. Four years later, although the frequency of problematic behaviors did not lessen, the counseled caregivers were significantly less likely to react negative-
Caregivers: A Portrait in Numbers

**WHO ARE THEY?**

- **Estimated Total in the U.S.**
  - 43.5 million

- **Race & Ethnicity**
  - Hispanic adults report the highest prevalence of caregiving responsibilities: 21% care for a loved one vs. 20.3% of African-Americans, 19.7% of Asian-Americans and 16.9% of whites

- **Gender**
  - At least 60% are female

**WHO THEY TEND AND WHAT THEY DO**

- Nearly 50% of those caring for adults do so for a parent or parent-in-law
- 12% tend a spouse or partner
- 15% care for a non-family member
- Female caregivers are more likely to provide personal care: 56% help with dressing and 31% with bathing vs. 24% and 17% for men

**HOW MUCH TIME DO THEY DEVOTE?**

- **Weekly Hours**
  - Family caregivers spend an average of 24.4 hours per week, but nearly 1 in 4 spends 41 hours or more providing care

- **Duration**
  - The average length of a caregiver's role is 4 years. 50% of caregivers provide care for a year or less, and 24% provide care for 5 years or more

**COSTS & BENEFITS**

- **Work/Income**
  - Women give up an estimated $324,000 in earnings on average; men lose $284,000
  - Female caregivers are more likely to stop working (12% vs. 3% for men) or take a less demanding job (16% vs. 6%)
  - Single women caring for their family members are 2.5 times more likely than non-caregivers to live in poverty in old age

- **Health**
  - 72% of family caregivers report not going to the doctor as often as they should, and 55% say they skip doctor appointments for themselves
  - 63% report poor eating habits
  - 58% say they exercise less than before taking on caregiving
  - 40% to 70% have clinically significant symptoms of depression; a quarter to half of this group meet the diagnostic criteria for major depression

- **Rewards**
  - 81% of those caring for dementia patients reported "gains" as well as "strains."
  - The main benefits: spiritual growth, personal growth, feelings of mastery and accomplishment

**WHAT DO THEY NEED?**

- **Assistance**
  - 84% of caregivers say they need more help and better information; one third say they have no help, paid or unpaid

- **Biggest Worries**
  - Keeping their loved one safe (42%)
  - Managing their own stress (42%)
  - Making end of life decisions (22%)

---

ly (such as getting angry). This matters because studies have shown that caregivers' subjective evaluations of their main sources of stress were better predictors of how well they fared than the actual frequency of those stressors.

Another powerful strategy is to focus on boosting rewards. Classic research has found that if dementia caregivers list things their loved one used to enjoy or that they enjoyed together—walks in the park, eating ice cream, dancing to oldies—then do them again, both care partners experience an uplift and a reinforcement of their closeness. More recently, a pilot study by Stanford University research professor and psychologist Dolores Gallagher-Thompson and her colleagues found that in caregivers of people of different ages with intractable depression, shared, happy activities benefited the caregivers' well-being.

Gallagher-Thompson also co-authored a 2013 study with dementia caregivers that involved scheduling pleasant events and enhancing communication between care partners. The experiment found that the 29 caregivers who had this kind of "enhanced behavioral activation" added to a standard psychoedu-
cational program had decreased depression compared with a control group of 30 caregivers who had not been coached to schedule pleasant events with their care partners.

Managing Stress with Social Support

"The hardest part is getting myself to breathe some days," says Wendi Steines. At age 44, Steines is the divorced mother of 14-year-old Nicholas and 11-year-old Adam, both of whom have autism spectrum disorder, along with other behavioral syndromes. She has not participated in an organized intervention but has joined parent seminars and autism groups and has read widely, cobbled together her own self-help program composed of many of the elements tested in universities.

Part of her strategy is strong social support. Many interventions work to fortify this critical element. For example, counselors in the New York University Caregiver Intervention for Adult Children, designed to help people tending to parents with dementia, hold individual and family sessions that heighten support from a caregiver's social network—whether siblings, church members or old friends. In Steines's case, she developed her own strong moms' network in her local area, the New Jersey suburbs of Philadelphia. "We meet all the time, share a bottle of wine, laugh and babysit each other's kids," she says. The group helps her when she is sad and worried about her boys' futures and feeling overwhelmed by their symptoms.

Indeed, a British group led by psychologist Valerie Shilling of Brighton and Sussex Medical School carried out a qualitative study that put 12 parents, 23 "befrienders" (parents of a special-needs child trained to offer one-on-one emotional support to other parents), and 10 health care, social care and education service professionals in contact for one year. The study, published in 2015, found that shared experiences were central to how caretakers perceived peer support. The parents reported feeling greater emotional stability, personal growth and reduced isolation during the study. The befrienders also reaped benefits from their training, from mutual support and from the satisfaction of helping others.

Sometimes, however, caregivers must navigate their stressors alone. When, for example, Steines's "big sweetheart" Adam throws an hour-long fit over homework—screaming, flailing and kicking—she relies on behavioral strategies she has learned to increase the "up" moments with her boys and improve her own health, coping skills and happiness. Taking a deep breath and imagining her son's point of view, for example, helps her get through a difficult.
moment. Such skills may be crucially important. A 2015 study by University of Wisconsin—Madison researcher Jiunn Song and her colleagues, for example, found greater “cognitive aging” and memory problems among mothers in a sample of 128 midlife parents who had raised children with disabilities compared with 512 parents of children without disabilities. The investigators suspect that the difference was the result of “heightened parenting stress.”

Adding targeted stress-reduction techniques such as meditation and mindfulness training to a program of behavioral management is now showing particular promise both for parents like Steines and for caregivers of the elderly, according to several studies by Nirbhay N. Singh of Augusta University.

Technology may help. Although studies in this area are lacking, researchers such as Gallagher-Thompson encourage the use of smartphone apps to access guided meditation such as Calm and Headspace, as well as a series from British hypnotherapist Glenn Harrold. Steines makes use of these apps herself and reports that her boys like them, too.

Respite Can Refresh

Of the four critical characteristics of successful caregiving—mastery, coping skills, social support and reducing physical stress—the last is the latest to be studied. And researchers have recently proved that stepping away from caregiving on regularly scheduled mornings or days off can bring measurable relief.

Investigators of the Daily Stress and Health (DASH) study, led by Zarit, have tested this idea, with remarkable results. Zarit and his colleagues interviewed and tracked the hormone cortisol in 158 family caregivers of a person with dementia. They wanted to examine how the individuals’ perceived and measured stress changed when they could take breaks from their duties by bringing their charges to a social adult day center for people with dementia.

The study, which was published in the Gerontologist this year, found that regular breaks for caretakers resulted in

Anatomy of an Intervention

Among the most successful approaches to helping caregivers is the New York University Caregiver Intervention (NYUCI), designed to support people tending to loved ones with dementia. The program was based on work in the late 1990s by N.Y.U. psychiatric epidemiologist Mary S. Mittelman. A key measure of its efficacy is the fact that caregivers in the program are able to successfully tend to their loved ones at home far longer than nonparticipants, delaying the need for institutionalization. Positive results from NYUCI have now been found in interventions in five states.

University of Minnesota gerontologist Joseph Gaugler and his colleagues have adapted NYUCI for adult children caring for parents. In 2013 they reported that just 37 percent of the adult-child caregivers who participated placed their parent in a facility versus 66 percent in the control group. Caregivers also reported better quality of life, reduced depressive symptoms and less stress in response to disruptive behaviors.

NYUCI is a multipronged program that includes referrals to support groups and mindfulness programs. The chief component is a series of individual and family therapy sessions targeted at problematic psychological dynamics within the caregiver and among family members. In addition to regularly scheduled sessions, participants can reach out for ad hoc counseling by telephone whenever they need it, whether Dad with dementia is screaming through the hallways at night or the caregiver’s brother is accusing her beset sister of trying to “put Mom away.” Across cultures, family dissonance has long been shown to increase caregiver strain. A classic 1953 study found that for married caregiving daughters, siblings were both sources of support and stress. And a 2014 study of 90 dementia caregivers in Colombia found that negative family dynamics were significantly associated with caregiver depression and stress.

Sheryl Fairbanks, 65, of Roseville, Minn., participated in Gaugler’s intervention in 2009. “I was caring 24/7 for four parents [her own and her husband’s] in three houses with an assortment of ailments, including my mother’s vascular dementia,” she recalls. Fairbanks had recently left a long career as a successful IT executive. Her sister, she says briefly, was “not available” for caregiving or to attend family therapy sessions. Fairbanks’s husband was her primary helper.

As part of the program, Fairbanks met for 90 minutes a month with family therapist Mark Reese, either at her home or at a nearby coffee shop. Reese helped her through diverse practical and emotional struggles over a period of 18 months. “Mark saved my life,” she says of the experience that ended in May 2012, when the last parent died. Reese rescued her from depression, she says, by helping her see the big picture and find meaning and pride in her situation.

The success of this program has led, this past July, to the creation of N.Y.U.’s Alzheimer’s Disease and Related Dementias Family Support Program, based in New York City. The state-funded program offers free counseling to caregivers in the area either in person, by videoconferencing or by telephone, depending on the caregiver’s preference. Mittelman is currently recruiting caregivers from across the country to participate in a study to determine if the videoconferencing version can match the results of the original, in-person program. (For online information, go to http://bit.ly/NYU2c2g.) If the remote intervention succeeds, it could reach many more people in need of support.

—F.R.
normal cortisol regulation on days of respite and better stress regulation overall, including higher levels of the anti-stress hormone DHEA-S the day after their break, even when on duty. The findings suggest that using adult day services for respite could improve caregivers' long-term health. Participants experienced less physiological stress on mornings before they took respite—perhaps because they were anticipating their next break.

Donald "Ed" Florida, a 77-year-old retired truck driver, was initially reluctant to take his wife, Ruth, to an adult day center after she was diagnosed with early Alzheimer's last year. He was afraid he would miss his spouse of 56 years. But his daughter endorsed the idea and suggested The Tender, a social day center for people with dementia in nearby Mount Laurel, N.J. After a few months, Ed began to appreciate the break and the time to get things done, especially as he took on more household tasks previously handled by Ruth, who is also 77. Meanwhile she can enjoy the social life, games and entertainment available at The Tender.

A 2013 Brigham Young University study of respite for couples with children on the autism spectrum also found impressive benefits. More respite care not only reduced daily stress but increased parents' caregiving uplifts and improved their marriages. Win, win, win.

Top Tips for Caregivers

Experts emphasize four key elements for managing the stress and maximizing the rewards of caregiving.

**Mastery:** Learn as much as possible about the disorder you are dealing with. The more you know about typical symptoms and behaviors, the better you can anticipate problems and not take them personally—all of which helps to build a sense of competence and control.

**Coping strategies:** Turn to advocacy and support groups, counselors and therapists to learn specific skills such as how to develop a more positive view of a loved one's behavior and how to think about one's own journey as a caregiver. Learn to focus on good care for your relative rather than making the person happy, which is often an impossible job.

**Social support:** Set aside any notion that you should be able to handle the responsibilities on your own. Reach out to family, friends, religious organizations, volunteer organizations and illness-specific support groups for sympathy, for humor and for hands-on help.

**Stress reduction:** Do exercise and do use respite programs. Also, try mindfulness training. Although working with an expert in meditation is ideal, apps such as Calm and Headspace can be helpful.

To find specific guidance on all these fronts, call or check the Web sites for caregivers and disease advocacy organizations. These are among the best:

- The Family Caregiver Alliance (www.caregiver.org) offers information and advice for every kind of caregiver.
- National Alliance on Mental Illness (www.nami.org) lends support for caregivers of people with bipolar disorder, schizophrenia, depression and other mental illnesses.
- Alzheimer's Association (www.alz.org) has local chapters providing education and support for every kind of dementia.
- Autism Speaks (www.autismspeaks.org) provides resources to parents of children with autism and to autistic adults.

The Power of a Plan

The vast majority of caregivers experience "gains" as well as "stains" from the experience, which includes 81 percent of people caring for dementia patients, according to a 2005 study by University of Iowa professor of social work Sara Sanders. In her study, caregivers reported three kinds of benefit: spiritual growth and increased faith, personal growth, and feelings of mastery and accomplishment.

As researchers further investigate what makes these experiences rewarding, the lessons learned can benefit many, whether people have access to a specific program or not [see box at left]. By consulting experts or advocacy groups and gathering knowledge, they can, like Wendi Steinos or the Alvarados, cobble together an informed approach to managing their responsibilities without losing themselves in their care for others.

The Support, Health, Activities, Resources and Education (SHARE) program, based at the Benjamin Rose Institute on Aging in Cleveland, offers some insight into how empowering planning ahead can be. Over the course of SHARE, counselors offer people with early-stage dementia and their caregivers five to six sessions in which the care partners learn about how the disease progresses, what decisions will need to be made at each point, and what support family, friends or professionals might provide.

Working together, the counselor and care partners develop a practical, written plan that the caregiver can refer to when the person with dementia can no longer adequately express preferences. This plan is a potent tool to relieve caregivers' feelings of guilt or inadequacy when they need additional help. Preliminary findings of controlled trials of SHARE, according to its principal investigator Carol Whitlatch, are that after counseling, caregivers take advantage of more services to help them cope. They also have a greater understanding of and better communication with their relative, compared with members of a control group who received a single information session. Although SHARE...
As his wife's Alzheimer's has progressed, Donald "Ed" Florida has taken on many of her chores. He has learned supportive strategies from caregivers at The Tender, a center for dementia patients that she attends.

The choice was not easy. "I'm so afraid of hurting my husband's pride," she says, "when he looks around and sees the other people who are there. Jim has led a life of the mind, and now he's losing that." She might not have been able to take this step had she and Jim not attended SHARE, at which point Jim insisted that he did not want to burden his loved ones. He wanted Nancy to accept help.

As his condition progresses, the Scotts will face more challenges. But by banding together as a family, making informed decisions, supporting each other and seeking help as needed, they can better weather what lies ahead. Making a plan for Jim has also helped Nancy to envision her own future. She recently became a grandmother and is setting aside time to enjoy her new granddaughter, Meredith. She also hopes to become involved in Alzheimer's advocacy. "I try to think about my life and how I'll do it," she says. "I want to come out the other side still vibrant and healthy." Given the new science from which she has benefited and the choices she has made thus far, her odds look good.

MORE TO EXPLORE

- Family Caregiver Stress Relief. Online video. Home Instead Senior Care, May 17, 2013. www.youtube.com/watch?v=xaonoH1XqNI
- From Our Archives