

Dementia: Supporting Caregivers

Author: Susan Walters Schmid, PhD and Stephanie Zeman, RN, MSN

Contact hours: 1.5

Course price: \$19

Course Summary

This course responds to a growing public health concern for those who are caregivers of people with dementia. With growing responsibility for ADLs and IADLs, caregivers find themselves in isolation. Social frameworks including the CARE Act and the RAISE Family Caregivers Act are designed to support caregivers. Practical advice includes learning how caregivers want to receive information and transferring information on medical/nursing tasks and medication management. Finally, this course addresses the role of assessments, mental health and emotional support, and managing stress, while advising that caregivers find ways to take a break from these sometimes-onerous duties.

Instructions for Mail Orders

To print everything you need, including the test, evaluation, and registration, click the Print and Go link next to the course on the curriculum page. Study the course, pass the test, and fill out the forms.

Make out your check or money order to ATrain Education, Inc. or enter your credit card information on the form provided.

Mail the completed forms with your payment to:

ATrain Education, Inc

5171 Ridgewood Rd

Willits, CA 95490

When we receive your order, we will grade your test, process your payment, and email a copy of your certificate. For a paper copy of your certificate (suitable for framing), please add \$8.50 to your payment.

Questions? Call 707 459-1315 (Pacific Time) or email (contact-us@atrainceu.com).

Course Objectives

When you finish this course, you will be able to:

1. State 3 reasons why caregiver support is a public health concern.
2. List 4 challenge for healthcare providers working with dementia care recipients their caregivers.
3. Name 5 ways you can support caregivers who are caring for patients with Alzheimer's disease and other dementias.
4. Name 6 risks for caregivers as they are providing support for people who have dementia.

Criteria for Successful Completion

80% or higher on the post test, a completed evaluation form, and payment where required. No partial credit will be awarded.

COI Support

Accredited status does not imply endorsement by ATrain Education or other accrediting agency of any products discussed or displayed in this course. The planners and authors of this course have declared no conflict of interest and all information is provided fairly and without bias.

Commercial Support

No commercial support was received for this activity.

1. Caregiving Today

As the number of older Americans increases, so will the number of caregivers needed to provide care. . . . Currently, there are seven potential family caregivers per adult. By 2030 there will be only four potential family caregivers per adult.

CDC, 2019b

A **caregiver** is a person who provides direct care to another who requires assistance with everyday tasks to function in daily life. Care recipients can include children, people with disabling conditions, and older adults. **Formal** caregivers are members of a formal service system, whether paid or unpaid.

Informal (family) caregivers are “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance” to the recipient. Informal caregivers can be primary or secondary caregivers and may or may not live with the recipient (FCA, 2014). Almost always unpaid, informal caregivers make up the vast majority of their cohort.

Family caregivers share certain responsibilities, challenges, and rewards regardless of the conditions or illnesses of their loved one but caregivers of patients with dementia face a number of additional challenges and potential stressors.

Nearly half of all caregivers of older adults do so for someone with Alzheimer’s or another dementia. While 1 in 5 caregivers of older adults reports a decline in their own health due to caregiving responsibilities, among those caring for someone with Alzheimer’s the proportion is 1 in 3 (CDC, 2019).

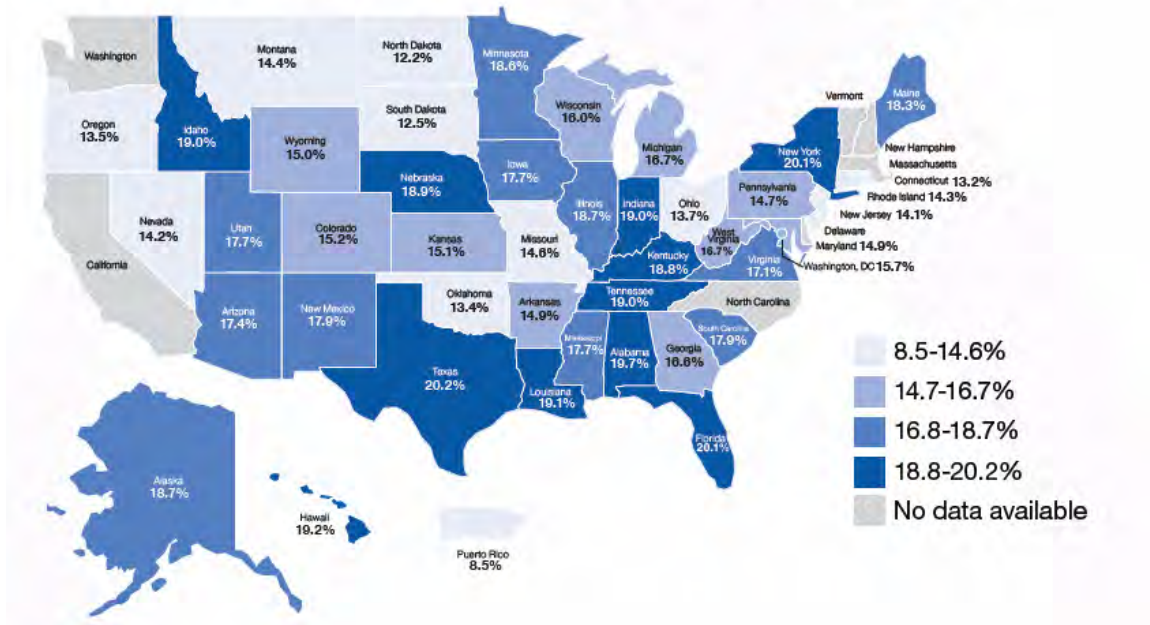
In 2017, 16 million family members and friends provided 18.4 billion hours of unpaid care to people with Alzheimer’s and other dementias, at an economic value of more than \$232 billion. In just the next year those figures increased to more than 16 million family members, 18.5 billion hours, and \$234 billion, respectively (CDC, 2019; AlzA, 2019b).

Approximately two-thirds of dementia caregivers are women, 34% are age 65 or older, and about 25% are also caring for children under age 18. Dementia caregivers provide care for a longer time period than do caregivers for those with other conditions—more than 50% provide care for 4 years or longer (CDC, 2019c).

As the population ages and the number of people with Alzheimer’s disease and other dementias increases so too will the need for more caregivers (CDC, 2019b,d). Although some research suggests that in the United States and other higher-income Western countries the prevalence and incidence of Alzheimer’s has declined in the last 25 years, globally the total number of people with Alzheimer’s and related dementias is increasing. And low- and middle-income countries will bear the brunt (68%) of the projected increase in the global prevalence and burden of dementia by 2050. In those countries there is no evidence that the risk of Alzheimer’s and other dementias has been declining (AlzA, 2019b).

Estimating Future Caregiving

Figure 6: Non-caregivers aged 45 years or older who expect to be caregivers within the next two years



Source: CDC, 2019d.

Challenges and Rewards of Caregiving

Caregiving can be both challenging and rewarding, often at the same time. Caregiving can result in emotional stress, depression, and negative effects on employment, income, and financial security for caregivers. Yet, caregiving proves to be a rewarding experience for many and can bring family members closer together (CDC, 2019, 2019b,c; Robinson et al., 2019).

The challenges of caregiving for a person with Alzheimer's or other dementia (ADRD) often include:

- Overwhelming emotions as the patient's capabilities decrease
- Fatigue and exhaustion
- Isolation and loneliness
- Financial and work complications

While rewards for caregivers can include:

- Bonding with patient deepened through care, companionship, and service
- Improved problem-solving and relationship skills
- Formation of new relationships through support groups
- Unexpected rewards that develop through compassion and acceptance (Robinson et al, 2019)

Acquiring more knowledge about the disease and its expected progress can reduce caregiver frustration by allowing for planning and preparation supported by reasonable expectations. Information about disease progression is one of the things caregivers are most interested in receiving (Slaboda et al., 2018; Robinson, 2019).

For healthcare professionals who would like more statistics for themselves or to support action by or in their practice, facility, or community, the CDC provides broad access to data about caregivers and their situations, most recently from 2015–2017 through the Behavioral Risk Factor Surveillance System (BRFSS). Information is available for the United States as a whole, as well as by region and state, and reports can be generated and viewed through the Alzheimer's Disease and Healthy Aging Data Portal (CDC, 2019d, e).

Caregiving and Public Health

The Centers for Disease Control (CDC) notes public health can play an important role in supporting caregivers by helping to expand, promote, and tailor resources in these areas:

- Community-based programs for physical activity, chronic disease self-care, and caregiver education;
- Peer support groups and social gatherings for people affected by dementia;
- Online support and information resource centers;
- Apps for caregivers and persons living with dementia and GPS tracking devices;
- Home healthcare services and home modification programs;
- Adult day and respite care;
- Advanced care and advanced financial planning;
- Transportation services; and
- Information and referral services (CDC, 2019)

According to the Alzheimer's Association, more and more communities in the United States are taking a public health approach to Alzheimer's disease and other dementias because:

- The burden is large.
- The impact is major.
- There are ways to intervene. (AlZA, 2019)

The number of Americans living with Alzheimer's is expected to grow, so that by 2050 there may be as many as 14 million living with the disease. The financial burden could exceed \$1 trillion and two-thirds of that would be borne by federal and state governments through Medicaid and Medicare (AlZA, 2019).

While Alzheimer's and other dementias are not preventable at this time, some impacts are. Research shows that more than one-quarter of all hospitalizations of people with dementia are preventable, and that 95% of those with Alzheimer's and other dementias have another chronic condition like heart disease, diabetes, or stroke. The complications arising in management of this situation often result in poorer health outcomes and higher costs (AlzA, 2019).

The potential impacts of Alzheimer's and other dementias can be mitigated with a strong public health response. This response can help support early detection and diagnosis, reduce risky health behaviors, collect and use surveillance data, develop workforce competencies, and mobilize community partnerships (AlzA, 2019).

The CDC and the Alzheimer's Association have worked together to develop the Healthy Brain Initiative (HBI). The initiative's guidebook—*State and Local Public Health Partnerships to Address Dementia, the 2018–2023 Road Map*—offers a detailed plan that state and local public health agencies and their partners can use. Many of the twenty-five actions in the Road Map can help meet the needs of caregivers, and it also promotes education and support for healthcare providers as they work with caregivers (AlzA, 2019; CDC, 2019).

The Road Map section entitled "Assure a Competent Workforce" includes:

- **W-2** Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.
- **W-3** Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.
- **W-4** Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.
- **W-7** Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services. (CDC, 2019)

It is critical that our perception of caregiving encompass the joint roles and importance of family caregivers and healthcare providers in working toward the best possible outcome for a patient. Research has demonstrated the critical value of training for both caregivers and healthcare providers.

Alzheimer's: An Emerging Public Health Issue (Video) 9:30

https://www.youtube.com/watch?time_continue=30&v=f0a8KuYlpy4

2. The Healthcare Professional's Challenge

Emergency room staff call it a "pop drop"—when a disabled older person comes in for medical attention, but it seems like the person who takes care of them at home is also seeking a break from the demands of caregiving.

Michigan Medicine, 2017

Healthcare providers treating older adults with family caregivers have, in a sense, two sets of "patients" (Brodaty & Donkin, 2009; Reinhard et al., 2019). While the needs of care recipients may be the original, and at first most obvious, focus, caregivers also need strong support. This critical need covers two domains:

- **The caregiver is the client** with the work of the provider meant to help reduce caregiver distress and the overall impact of caregiving on their health and well-being. In this case the caregiver receives the direct benefit and the care recipient benefits only secondarily.
- **The caregiver is supported in caring**, becoming more competent and confident in providing safe and effective care to the patient. This benefits the patient but can also indirectly reduce caregivers' stress by reducing their load and/or increasing their sense of mastery (Reinhard et al., 2019).

Reinhard and colleagues* looked at the first of these roles in depth. They noted that many years of research had validated the needs but programs to address them were lacking. Today we face continually increasing numbers of both dementia patients and caregivers, as well as increasing demands on healthcare providers to deal effectively with both groups. More research-backed interventions and support programs for caregivers, and the healthcare providers working with them, are available, but there is still much room for improvement.

* In "Supporting Family Caregivers in Providing Care"—a chapter in *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*, 2008).

With 15 million American family caregivers of those with dementia, the well-documented physical and emotional toll on them has not led to efforts to integrate their support into care for their recipients. Burden and fatigue of caregivers has been shown to intensify the high use of hospitals and emergency departments (EDs) by dementia patients and the much higher cost of care for those patients when compared with patients with heart disease or cancer (Slaboda, 2018; MI Med, 2017).

As healthcare practices and facilities focus more and more on managing costs, the need to provide *more* care rather than less calls for an emphasis on what works and can save time and money in the long run. Supporting caregivers of patients with ADRD is something that works and can facilitate long-term benefits for everyone.

Why Be a Caregiver and Who Does It?

Family caregivers provide care for a variety of reasons, including:

- A sense of love or reciprocity
- Spiritual fulfillment
- A sense of duty

- Guilt
- Social pressures
- On rare occasions, greed

Those who are motivated by duty, guilt, or social pressures are more likely to resent their role and experience greater psychological distress than those whose motivations are more positive. A caregiver who identifies more benefits of the role will experience less burden, better health and relationships, and greater social support (Brodaty & Donkin, 2009).

Negative experiences of caregiving often receive more attention but, as noted above, caregivers also identify **positive feelings** and outcomes, including:

- Togetherness and shared activities
- Bonding
- Personal and spiritual growth
- Feelings of accomplishment and mastery

Views of the caregiving role are affected by gender, age, education, and ethnicity. Levels of stress vary with characteristics of the caregiver—gender, being a spousal caregiver, other life events, physical health, family history of mental health issues, quality of relationship with care recipient, life satisfaction, low levels of self-esteem and mastery, high neuroticism, the disease stage, and needs experienced by the care recipient (Brodaty & Donkin, 2009).

Increasingly, caregivers are from diverse backgrounds and experience the role differently depending on a variety of factors. Responses to stressors as well as receptivity to information, support, and interventions are not monolithic. Recent research that looks at experiences by generation (Silent, Boomer, X, Millennial, Z) as well as ethnicity and race, marital status, employment status, education, and income, points to real differences among all these groups in perception of the role and the effects of stress. In addition, about 50% of family caregivers are performing complex care—medical/nursing tasks—which changes their experience even more (Reinhard et al., 2019).

What's a Provider to Do?

As this class will examine, education and training materials targeted to caregivers are widely available, especially online, yet most research identifies a real lack felt by caregivers when it comes to information they need to feel confident about their caregiving. This suggests a fundamental issue with communication between family caregivers and the many “others” they encounter in their journey—healthcare providers, social services providers, and other community resources. But this is something that can be changed and improved with careful attention to what is needed and how to get it, and about the different ways that people learn.

Home Alone Revisited: Family Caregivers Providing Complex Care (Reinhard et al., 2019) identified a number of recommendations that speak to private industry, community-based organizations, researchers, and members of the healthcare and social services sector. The latter includes:

- Increase awareness of the current realities for family caregivers among the general public, health care professionals, health care delivery systems, and policy makers.
- Update assessment tools for family caregivers to include medical/nursing tasks and capture the complexity and trajectory of care.
- Public programs should include assessments of family caregivers who are providing complex care for consumers who identify these caregivers in the person-centered plan of care.
- Health care and social service professionals must elicit and respond to the worries of these family caregivers.
- Health care systems and professionals must make stronger efforts to recognize family caregivers and offer them instruction on and support for complex care.
- Health care and social service professionals must recognize that family caregivers are diverse in many ways and need proactive outreach to help them manage complex care.
- Health care and social service professional education must include preparation to support family caregivers who provide complex care. (Reinhard et al., 2019)

Not all of these suggestions can be accomplished by every provider equally, but the key message is that caregiving is in fact a **community** project—a public health concern—in which all members need support.

3. Helping Caregivers Help Recipients

Knowing that caregivers are increasing in number and diversity and also in the tasks they need to be prepared to accomplish, what can healthcare providers do assist them?

Categories of Care

Training and support is needed by caregivers to:

- Provide general care for their patients' ADLs and IADLs
- Provide medical/nursing tasks (M/Ns)

Activities of Daily Living (ADLs)—walking/ambulating, feeding, dressing and grooming, toileting, bathing, and transferring—often seem obvious because we are used to doing these things for ourselves, but there are learned techniques and methods for helping someone else with these activities that can make them easier and safer for both people.

Instrumental Activities of Daily Living (IADLs)—managing finances, managing transportation, shopping and meal prep, housecleaning and home maintenance, managing communication, and managing medications—may also seem obvious, but will also often benefit from new techniques and information.

Assessment of ADLs and IADLs give geriatricians and primary care providers information on how an older person is “functioning,” and difficulties can point to physical or cognitive problems that should be addressed (Kernisan, 2019).

Medical/nursing tasks (M/Ns) represent complex care and can include (in order of frequency): managing medications (82%), helping with mobility assistive devices (51%), preparing food for special diets (48%), wound care (37%), use of meters and monitors (34%), operating durable medical equipment (27%), using incontinence supplies (25%), operating mechanical ventilators or oxygen (11%), other tasks include using telehealth equipment, incontinence equipment such as catheters, or suctioning equipment; administering IV fluids or medications, test kits, or enemas; operating tube feeding equipment or home dialysis equipment; and doing ostomy care (Reinhard et al., 2019).

Caregivers performing M/Ns are frequently performing more than one, with more than 60% performing 3 to 5 tasks. These caregivers are also twice as likely to be assisting with ADLs, handling a greater number of IADLs, and spending more hours caregiving than those who do not perform any M/Ns (Reinhard et al., 2019).

Most family caregivers are performing ADLs and, if not performing all IADLs, are responsible for locating and hiring people who can do them safely, correctly, and in a trustworthy manner. Caregivers may not realize there are safer or more efficient ways to accomplish some of these tasks for another person until something is lost or someone is injured. Providing resources for caregiver education on these tasks is important.

How Caregivers Want to Receive Information

A recent study using focus groups found that caregivers were interested in having more information about what to expect at every stage of their care recipient's illness

and about managing behavioral changes, coexisting medical conditions, and possible complications. Caregivers looked first and foremost to healthcare professionals as the primary source of trusted information (Slaboda et al., 2018).

Caregivers preferred information that came in:

- Peer-to-peer discussion forums
- Fact sheets
- Checklists
- Educational videos (Slaboda et al., 2018)

Despite a wealth of information in these formats available on the internet from organizations such as the Alzheimer's Association, Family Caregiver Alliance, AARP, and others, more than half of the study members did not use online tools. More research is needed to understand why desired materials are available online yet so many people do not use them (Slaboda et al., 2018).

In the meantime, healthcare providers, knowing they are considered a trusted resource, can prepare themselves to help caregivers connect with online resources, or help them locate good alternatives if computers and internet access are barriers to use. Local hospitals, senior centers, community colleges, and libraries may have printed material, regular visiting experts, workshops, classes or seminars, and may facilitate support groups.

Online research can arm you with resources you feel most comfortable recommending and that complement the needs of your position and practice. Keep in mind that too much information can be overwhelming and if a person is unsure about the accuracy or reliability of material they may lose out on useful information; directing caregivers to resources you are familiar with and have confidence in can help them focus. Remind them to keep track of their questions and use those to expand your resource collection and inform future practice.

Organizations such as AARP, the Family Caregiver's Alliance, and the Alzheimer's Association are some of many sources of information (see Resources). Each organization lays out their material differently and may be appealing to different users. Printer-friendly versions, mailed copies, or material in other languages are often available.

The Alzheimer's Association has online information for professionals on assessment, diagnosis, management, and care planning, as well as information professionals can refer patients and caregivers to on what to expect at each stage of the disease—improving communication, relevant legal and financial planning, driving issues, understanding and responding to dementia-related behavior, modifying activities, daily planning, safety, planning for costs, and the choice in residential facilities. In addition to online training and materials, they provide links to local chapters and online and in-person support groups (AlzA, 2019c).

Family Caregiver Alliance has an online Learning Center with materials to read—online or print out; watch webinars, videos, slide shows; listen to meditations or teleconferences. They also offer some state-specific information on getting help, links to events in certain areas, and online classes (FCA, n.d.).

Support for Caregiving Tasks

Care Plans

Healthcare providers can work with caregivers to establish a care plan utilizing the Complete Care Plan form available from the CDC (in English and Spanish), or a similar form that helps the caregiver gather information about:

- Health conditions
- Medications
- Healthcare providers
- Emergency contacts
- Caregiver resources

Emphasize the benefits to both caregiver and care recipient of keeping an up-to-date plan. Suggest to caregivers that having a system for recording information, whether paper or digital, is important for keeping information current, for themselves, for healthcare providers, and others who may be called upon to step in to help with care. Systems may use paper in notebooks or binders, Word or Excel documents, online programs, or even phone apps, but resources and support discussions suggest that the system that is going to work best is the one a caregiver is adept at using and will keep up to date.

ADLs and IADLs

Some ADLs and IADLs may be straightforward for a caregiver to begin handling. Shopping for food and meal preparation or arranging transportation to appointments are generally similar to what we do for ourselves and simply a matter of learning details relevant to the patient. Other activities like bathing, dressing, and transferring are not the same as doing those things for oneself and require learning some new skills. Techniques for managing ADLs for another person are particularly amenable to educational videos—one of the preferred methods of learning identified by caregivers.

Helping another person to move from or to a bed, chair, or toilet can be dangerous if not done properly—an important concept to convey to caregivers. The video below on transfer skills, created by the Family Caregiver Alliance, is a good example of how new skills can be learned relatively easily at home, and a video is always there to be watched again.

Video: Ch. 1: Transfer Skills (Caregiver College Video Series) 6:19

<https://www.caregiver.org/ch-1-transfer-skills-caregiver-college-video-series>

Other videos in the Caregiver College Video Series reflect a mix of ADLs and IADLs and include Nutrition, Dental Care, Bathing and Dressing, Toileting & Incontinence, Behavioral Issues, and Self-Care.

Another video library is available from the Home Alone Alliance's Family Caregiving How-To Video Series (Reinhart et al., 2019), which includes multiple videos in the categories of Special Diets, Managing Incontinence, Wound Care, Mobility, and Managing Medications. Subtopics are covered in collateral videos and guides in PDF

format are available along with fill-in forms that can be downloaded and used by caregivers.

Sometimes topics related to ADLs and IADLs are particularly sensitive and hard for caregivers and care recipients to discuss, especially if the caregiver is a spouse or child. One of these topics is driving—and how to convince someone to stop driving. Approaches that emphasize dignity and respect and tap into important values held by the care recipient can be effective as this video demonstrates.

Video 5:42. How to Take the Keys

https://www.youtube.com/watch?v=gr_47LOFp7M

As the needs of the care recipient increase, caregivers feel more stress as they worry that they do not know how to do something, are not doing it correctly, or will do something to cause pain or suffering to their loved one (Reinhard et al., 2019). When helping with ADLs and IADLs morphs into helping with more complex medical/nursing tasks, caregiver stress usually increases.

Medical/Nursing Tasks (M/Ns)

The most common medical/nursing task that caregivers perform is medication management (as identified by 82% of participants in a recent study). Just over half of them noted they had to do it more than once a day and slightly more than one-quarter of them considered it hard to do (Reinhard et al., 2019).

Medication Management

Depending on the source, medication management is considered with IADLs or with M/Ns, reflecting how it comes to be part of a person's daily routine and how it can vary from a simple need to take a pill or two once or twice a day, to a very complex undertaking involving multiple medications multiple times a day that may include pills, liquids, drops, patches, sprays, ointments injections, and suppositories.

Medication management involves a complex of skills to keep track of what is being taken and when it changes; manage refills; see that medications are dispensed on time, not forgotten, and taken correctly; follow safety practices so that a patient with cognitive deficits cannot access medications; and know how to deal with patient resistance to medications. It also means being aware of potential side effects, knowing what to do about them, and how to spot them in a patient with dementia who may not be able to communicate well.

Several websites offer videos, fill-in forms, and guides for handling medication management, including dealing with resistance by patients with dementia. These include Home Alone Alliance and Next Step in Care (see Resources).

Other Tasks

Other M/N tasks commonly performed by at least 25% of caregivers include help with assistive devices for mobility, preparing special diets, wound care, using meters/monitors, operating durable medical equipment, and using incontinence supplies such as disposable briefs. Except for wound care, 27% to 54% of caregivers do these tasks more than once a day and one-third to one-half of caregivers identify them as hard to do (Reinhard et al., 2019).

More than one-quarter (27.5%) of caregivers identify tasks as difficult because they are afraid of making a mistake. This fear is highest for managing medications, using meters and monitors, and performing wound care. The constant attention needed for

tasks like special diets and medication management and the fear of hurting the care recipient factors into wound care, mobility, and the use of durable medical equipment (Reinhard et al., 2019).

Managing incontinence with disposable briefs is cited as the most emotionally challenging with one-third of caregivers noting embarrassment for the care recipient and 20% finding the task emotionally difficult for themselves (Reinhard et al., 2019).

As noted earlier, good video libraries for learning or perfecting techniques for many common caregiving tasks are available online. Videos that address incontinence, for example, do so with compassion and treat the problem broadly to help a caregiver think about the situation ahead of time, be prepared, and know when explanations may not be the obvious.

Ask caregivers what tasks they are performing and whether they feel comfortable doing so. If their loved one was recently discharged from the hospital, find out how much training the caregiver received and if the patient qualifies for Medicare home health, which can be another source of instruction.

Special consideration should be given to pain management, which is a high-stress task. Seventy percent of family caregivers handling M/N tasks are faced with managing pain or discomfort for their care recipient and 80% rate pain management as stressful. Pain management is a full-attention task with many variables. Maintaining control and knowing what is too little or too much can be highly stressful, with men reporting more difficulties and worry about pain medications than did women (Reinhard et al., 2019).

Medical/Nursing Tasks and the CARE Act

More and more, caregivers are finding themselves responsible for medical or nursing tasks when a loved one is discharged from the hospital and often they do not know how to do these things, may not understand the instructions, or may not receive any instruction. Introduced to state legislatures by AARP in 2014, the Caregiver Advise, Record, Enable (CARE) Act is now law in 40 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. As of 2019 it is also under consideration in Wisconsin. The CARE Act requires hospitals to:

- Ask each patient if he or she wishes to name a family caregiver.
- Record the name of the family caregiver on the patient's medical record and inform the caregiver when the patient is being discharged.
- Provide the caregiver with education and instruction on the medical or nursing tasks that will need to be performed at home. (AARP, 2019)

The CARE Act is intended to help caregivers to finally be recognized as "part of a patient's overall health team" (AARP, 2019). However, the report *Home Alone Revisited: Family Caregivers Providing Complex Care* released in April 2019 makes it clear that much still needs to be done. The study's five Major Findings provide some followup on the CARE Act and are illuminating:

- #1: Today's caregivers provide *intense and complex* care, including medical/nursing tasks and managing multiple health conditions that are often accompanied by pain.

- #2: Today's caregivers are *diverse* and so are their experiences.
- #3: Caregivers who are socially isolated or have no choice about caregiving are more *at risk* for experiencing difficulties with complex care.
- #4: Caregivers performing more medical/nursing tasks experience both *positive and negative impacts*.
- #5: Many family caregivers are still on their own—health systems should do *more to prepare* these vital members of the team. (Reinhard et al, 2019)

The Next Step in Care website has materials including a toolkit that are especially directed toward hospital-based providers who are working with or want to work with family caregivers (see Resources).

Caregivers and the RAISE Family Caregivers Act

The RAISE Family Caregivers Act (Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017,) which became law on Jan. 22, 2018, directs the Secretary of Health and Human Services to develop a national family caregiving strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers, and will include:

- Promoting greater adoption of person- and family-centered care in all healthcare and long-term service and support settings, with the person and the family caregiver at the center of care teams
- Assessment and service planning (including care transitions and coordination) involving care recipients and family caregivers
- Information, education, training supports, referral, and care coordination
- Respite options
- Financial security and workplace issues (ACL, 2019)

The advisory council mandated to provide recommendations to the HHS Secretary has 15 members representing the diversity of stakeholders in family caregiving, including caregivers, healthcare and social service providers, and older adults using long-term services and supports. Background on all council members, meeting agendas and summaries, and livestream recordings of council meetings are available online (ACL, 2019, 2019a).

4. Helping Caregivers Help Themselves

Restrictions on resources may influence an agency's response to caregiver needs, but much depends on how we view caregivers in general. Are family members seen merely as a resource, or as people with needs and rights of their own?

FCA, 2006

Knowing how to provide care correctly to their care recipients helps caregivers feel less stressed. They are less likely to injure themselves when doing things such as lifting or moving someone, and knowing how to accomplish tasks efficiently and where to find help can save time. But caregivers also need to provide themselves with direct attention to their own mental, emotional, and physical well-being (*managing stress*); getting enough sleep, eating properly, and exercising; seeing their own healthcare providers for routine care and tests; and taking breaks from caregiving (*respite care*).

The Role of Caregiver Assessments

In 2006 the Family Caregiver Alliance's National Center on Caregiving published *Caregivers Count Too!: A Toolkit to Help Practitioners Assess the Needs of Family Caregivers*, which was the result of a consensus conference convened the year before. The toolkit is intended first, to sharpen the awareness of healthcare and social service providers about caregivers as an at-risk population with its own need for assessment; and, second, to help equip providers to develop and implement a caregiver assessment process appropriate to their practice (FCA, 2006).

Caregiver Assessment is a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources, and strengths of the family caregiver. It approaches issues from the caregiver's perspective and culture, focuses on what assistance the caregiver may need and the outcomes the family member wants for support, and seeks to maintain the caregiver's own health and well-being (FCA, 2006, 2014).

Reasons to conduct an assessment are that it:

- Builds caregiver morale and capacity: caregivers feel acknowledged, valued, and better understood; gain a better grasp of their role and what is required; and can identify whether strains are becoming too great
- Is the key to care planning: it is to know what is needed, what hasn't been dealt with, and where strain and health risks are at play; caregiver well-being can be key to a recipient staying in the community and not being institutionalized
- Opens doors for caregiver and care recipient: can establish eligibility for services and facilitate timely referrals
- Is a way to monitor program effectiveness and inform policy

While practitioner concerns about time and workload are legitimate, the toolkit makes a strong case that assessments will ultimately save time and resources and lead to better patient and caregiver outcomes (FCA, 2006).

In brief, any assessment should:

- Identify the primary caregiver and other family and friends who are involved in arranging, coordinating or providing care
- Approach issues from the caregiver's perspective
- Improve caregivers' understanding of their role and what they need to know to carry out tasks
- Give practitioners information to develop a care plan with measurable outcomes for caregivers
- Address services available for the caregiver and provide appropriate and timely referral for services
- Be no longer than necessary (FCA, 2006)

Assessments need to be tailored to your practice and the circumstances of patients and caregivers, but the toolkit provides detailed guidance for how to get there and how to focus on being practical, research-based, simple and direct, and systematic.

Mental Health and Emotional Support

Managing Stress

Stress is a serious and common issue for family caregivers and it can affect mental and physical health. You may see evidence of stress in your clients' behavior or they may self-identify with some or many of the signs of stress.

The lists that follow is a blending of the Mayo Clinic webpage, Caregiver Stress: Tips for Taking Care of *Yourself*, and the Alzheimer's Association caregiver stress pages, but they are very similar to lists that appear in many other places. Most discuss signs and specific support suggestions in some depth and may suggest practical manageable activities and goals, readings, videos, exercises, and support group options.

Healthcare providers will find there are many tip and support websites to choose from (see Resources) and, as with the earlier discussion of online resources, choosing key resources for your clients can help them focus on what is most important.

Psychologists and related practitioners may find the American Psychological Association's (APA) *Caregiver Briefcase* to be a useful resource.

Risks for Caregiver Stress

- Being female (but don't forget about the men)
- Having fewer years of formal education
- Living with the person you are caring for
- Social isolation
- Having depression

- Being in financial difficulties
- Higher number of hours spent caregiving
- Lack of coping skills and difficulty solving problems
- Lack of choice in being a caregiver (Mayo Clinic, 2018)

Signs of Caregiver Stress

- Feeling overwhelmed or constantly worried
- Feeling tired often
- Getting too much sleep or not enough sleep
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain, or other physical problems
- Abusing alcohol or drugs, including prescription medications (Mayo Clinic, 2018)

The Alzheimer's Association's *10 Symptoms of Caregiver Stress* provide a focus especially in tune with issues around care of a person with dementia.

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of concentration
- Health problems (AlzA, 2019a)

Dealing with Caregiver Stress

- Prepare for what is ahead by getting information and making care, legal, and financial plans ahead of time
- Ask for/accept help

- Focus on what you are able to provide/learn or update caregiving skills
- Set realistic goals
- Get connected
- Join a support group/talk to someone
- Seek social support/make use of community resources
- Set personal health goals/include regular exercise and relaxation techniques/get enough sleep (See Mayo Clinic, 2017 for more on relaxation techniques)
- See your doctor/take care of yourself
- Take advantage of respite care (AlZA, 2019a; Mayo Clinic, 2018; Robinson et al., 2019)

Respite Care or Taking a Break

Respite care is temporary care provided in a nursing home, hospice inpatient facility, or hospital so that a family member or friend who is the patient's caregiver can rest or take some time off. It can also encompass in-home respite care where home health aides come in to provide care normally handled by the family caregiver and adult care centers and programs (adult daycare).

Caregivers who are employed outside the home and are covered by the federal Family and Medical Leave Act may be eligible to use up to 12 weeks leave per year to care for a relative. This may be a good solution for a caregiver feeling particularly overwhelmed by caregiving responsibilities.

Programs of All-Inclusive Care for Elders (PACE)

Healthcare providers should be familiar with Programs of All-Inclusive Care for the Elderly (PACE) (Medicare & Medicaid) if they practice in the 31 states that offer it under Medicaid, making it available as well for those on Medicare who qualify (Medicare.gov, n.d.). Under PACE, a doctor may write a "prescription" for **respite care** that will be honored by Medicare. Among the many services are "social services, including caregiver training, support groups, and respite care."

Support Programs (Interventions)

The CDC, in collaboration with others, has developed the *Action Guide for using REACH OUT*, which is one of several evidence-based caregiver support system designed to promote the health and well-being of adults caring for person with dementia. While the guide is oriented toward those wanting to establish a program in their facility or community, the information provided can help any healthcare professional understand research fundamentals, elements of the problem, parts of a program and how it can work, and fundamental benefits. Information gained can be used to inform individual work with clients or if contemplating implementing a program.

5. Conclusion

As medical care becomes more complex and people live longer, the share of the population over 60 continues to grow, and the incidence of Alzheimer's disease and other dementias increases, many groups in society feel the effects and pressures. For the healthcare industry there are pressures both financial- and personnel-related. The number of providers with geriatric specialty training is not keeping pace with the growing need for that expertise. Some areas of the country and the world suffer real shortages of medical and community resources.

No doubt for healthcare providers it can be daunting to take on yet more responsibility but, in the long term, improving support to caregivers of those with Alzheimer's and other dementias (and to all family caregivers) stands to save everyone—individuals, communities, state and federal governments—time and money by reducing the need for emergency visits, hospital readmissions, and related services, and improving the quality of life for care recipients, caregivers, and all those who support them.

6. Resources and References

Resources

This list includes resources directed toward healthcare providers and also resources that caregivers can be directed to for information and training materials.

Professional Courses & Training Methods

Both of these companies provide training in specific methods of working and communicating with persons with age-related cognitive decline that emphasize dignity and respect. These are for agencies, professionals, para-professionals, and family caregivers. Materials include DVDs, publications, workshops, courses, seminars, etc., and some material is available at no cost. No endorsement is implied by listings.

Teepa Snow / Positive Approach® to Care

<https://teepasnow.com/>

Naomi Feil / Validation Training Institute

<https://vfvalidation.org/>

Organizational Resources

AARP

Family Caregiving / Caregiver Resource Center

<https://www.aarp.org/caregiving/>

Caregiver Stories

<https://www.aarp.org/caregiving/stories/info-2017/kim-campbell-caregiving-fd.html>

See also Home Alone Alliance.

Administration for Community Living (ACL) [was Administration on Aging (AOA)]

<https://acl.gov/>

Support to Caregivers

<https://acl.gov/programs/support-caregivers> (2019)

Eldercare Locator (assistance in locating services)

<https://eldercare.acl.gov/Public/Index.aspx>

Alliance for Aging Research

<https://www.agingresearch.org/>

<https://www.agingresearch.org/health-topic/alzheimers-disease/>

<https://www.agingresearch.org/health-topic/caregiving/>

Alzheimer's Disease: Helping Yourself Help a Loved One—Caregiver Workbook

<https://www.agingresearch.org/document/alzheimers-disease-helping-yourself-help-a-loved-one-caregiver-workbook/>

Alzheimer's Association

Educational material, and links to finding online and in-person support groups.

<https://www.alz.org/>

Training and Education Center – 14 courses, most directed to caregivers

<https://training.alz.org/home>

Caregiver Stress Check

<https://www.alz.org/help-support/caregiving/caregiver-health/caregiver-stress-check>

Alzheimer's and related Dementias Education and Referral Center (ADEAR)

<https://www.nia.nih.gov/health/about-adear-center>

Alzheimer's Foundation of America

Resources for professional training and caregivers, memory screening, and helpline.
<https://alzfdn.org/>

Alzheimer's Research Forum

News website and information resource dedicated to helping researchers accelerate discovery and advance development of diagnostics and treatments for Alzheimer's disease and related disorders.
<https://www.alzforum.org/>

American Psychological Association

Caregiver Briefcase
<https://www.apa.org/pi/about/publications/caregivers/index>

BrightFocus Foundation [was American Health Assistance Foundation (AHAF)]

<https://www.brightfocus.org/alzheimers>

Banner Alzheimer's Institute

<https://www.bannerhealth.com/locations/phoenix/banner-alzheimers-institute>
Dementia Dialogue / Alzheimer's Insights: Caregiver Tips
Institute's YouTube channel with 69 in-depth videos for caregivers.
https://www.youtube.com/playlist?list=PLnSXT-M_BnWkwLHt2jLkP6IU75wZZAJ51

Caregiver Bill of Rights

<https://caregiver.com/articles/caregivers-bill-of-rights/>

Centers for Disease Control and Prevention

Alzheimer's disease and caregiver resources.
<https://www.cdc.gov/aging/index.html>
<https://www.cdc.gov/aging/aginginfo/alzheimers.htm>
<https://www.cdc.gov/aging/caregiving/index.htm>
<https://www.cdc.gov/aging/caregiving/resources.htm>
<https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html>

Family Caregiver Alliance

<https://www.caregiver.org/>
Fact and Tip Sheets (several dozen on dementia and caregiver topics)
<https://www.caregiver.org/fact-sheets>
National Center on Caregiving (NCC)
<https://www.caregiver.org/national-center-caregiving>
Caregivers Count Too! Toolkit
An Online Toolkit to Help Practitioners Assess the Needs of Family Caregivers
<https://www.caregiver.org/caregivers-count-too-toolkit>
Caregiver College | 8 Video Series
https://www.youtube.com/playlist?list=PLa1B8idpEiEpIIAyH_swKvZvTQ9yAKH6t

HelpGuide

<https://www.helpguide.org>
Tips for Alzheimer's & Dementia Caregivers

<https://www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm>

Home Alone Alliance

Family Caregiving How-To Video Series

Includes such general topics as Special Diets, Managing Incontinence, Wound Care, Mobility, Managing Medications, with videos on multiple sub-topics, downloadable PDFs of Resource Guides, and most are in English and Spanish

<https://www.aarp.org/ppi/initiatives/home-alone-alliance/>

Inspire

Collection of “communities” (discussion forums) related to specific diseases and caregiving.

<https://www.inspire.com/>

Mayo Clinic

Searching on “Alzheimer’s” brings many pages a caregiver could use.

<https://www.mayoclinic.com>

National Academies of Sciences, Engineering and Medicine

Health and Medicine Division [formerly the Institute of Medicine (IOM)]

<http://www.nationalacademies.org/hmd/>

Search on “caregiving” for numerous resources useful to healthcare providers

Integrating Health Care and Social Services for People with Serious Illness: Proceedings of a Workshop

<http://www.nationalacademies.org/hmd/Reports/2019/integrating-healthcare-and-social-services-for-people-with-serious-illness-proceedings.aspx>

Study on Family Caregiving for Older Adults

<http://www.nationalacademies.org/hmd/Activities/Aging/FamilyCaregivingforOlderAdults.aspx>

National Alliance for Caregiving

<https://www.caregiving.org/>

<https://www.caregiving.org/innovation/>

National Hospice and Palliative Care Organization, CaringInfo Program

Caregiving

<https://www.nhpco.org/patients-and-caregivers/caregiving/>

National Institute on Aging (part of NIH)

Alzheimer’s Disease & Related Dementias

<https://www.nia.nih.gov/health/alzheimers>

Getting Help with Alzheimer’s Caregiving

<https://www.nia.nih.gov/health/getting-help-alzheimers-caregiving>

Alzheimer’s and related Dementias Education and Referral Center (ADEAR)

<https://www.nia.nih.gov/health/about-adear-center>

Next Step in Care (United Hospital Fund)

<https://www.nextstepincare.org/>

https://www.nextstepincare.org/Provider_Home/

Guides, Checklists, Videos – for family caregivers and providers in English, Spanish, Chinese, and Russian. A Toolkit for Working with Family Caregivers

<https://www.nextstepincare.org/providers/toolkit/>

Rosalyn Carter Institute for Caregiving

Print and online materials, links to outside resources, and online and in-person training for volunteers and healthcare providers.

<http://www.rosalynncarter.org>

<http://www.rosalynncarter.org/education-and-training/>

<http://www.rosalynncarter.org/resources/implementation-tools-and-guides/>

SymptomGuide Dementia

Phone app for Apple and Android for use by dementia caregivers.

<https://www.dementiaguide.com/>

References

AARP. (2019). Care Act Gains Ground: 3 more states adopt law to help family caregivers. AARP Bulletin. October 2019. p. 6.

AARP. (2019a). The Caregiver Advise, Record, Enable (CARE) Act. Map. Retrieved November 4, 2019 from <https://www.aarp.org/content/dam/aarp/ppi/2019/09/care-act-map.pdf>.

Administration for Community Living (**ACL**). (2019). RAISE Family Caregiving Advisory Council. Retrieved October 24, 2019 from <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>. Page has links to advisory council agendas, summaries, and live recordings of meetings.

Administration for Community Living (**ACL**). (2019a). Supporting Community Living with Caregiving Advisory Councils. Retrieved October 24, 2019 from <https://acl.gov/news-and-events/acl-blog/supporting-community-living-caregiving-advisory-councils>.

Alzheimer's Association (**AlzA**). (2019). The Public Health Approach. Retrieved October 25, 2019 from <https://alz.org/professionals/public-health/the-public-health-approach>.

Alzheimer's Association (**AlzA**). (2019a). Caregiver Health. Retrieved October 31, 2019 from <https://alz.org/help-support/caregiving/caregiver-health>.
<https://alz.org/help-support/caregiving/caregiver-health/caregiver-stress>
<https://alz.org/help-support/caregiving/caregiver-health/caregiver-stress-check>
<https://alz.org/professionals/public-health/core-areas/caregivers>
<https://alz.org/professionals/public-health/road-map>

Alzheimer's Association (**AlzA**). (2019b). Alzheimer's Disease Facts and Figures 2019. Infographic and full report. Retrieved October 26, 2019 from <https://alz.org/media/Documents/alzheimers-facts-and-figures-infographic-2019.pdf> AND <https://alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>.

Alzheimer's Association (**AlzA**). (2019c). Health systems and clinicians: Helping you enhance care and improve outcomes. Retrieved October 27, 2019 from <https://alz.org/professionals/health-systems-clinicians>.

Birkenhager-Gillesse EG, Doudewijn JK, Zuidema SU, Achterberg WP. (2018). The “more at home with dementia” program: a randomized controlled study protocol to determine how caregiver training affects the well-being of patients and caregivers. *BMC Geriatrics* 18, Article #: 252 (2018). Retrieved October 22, 2019 from <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-018-0948-3>.

Blom MM, Zarit SH, Groot Zwaaftink RBM, et al. (2015). Effectiveness of an Internet Intervention for Family Caregivers of People with Dementia: Results of a Randomized Controlled Trial. *PLOS|One*. February 13, 2015. Retrieved October 27, 2019 from <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0116622>.
<https://doi.org/10.1371/journal.pone.0116622>.

Brody H, Donkin M. (2009, June). Family Caregivers of People with Dementia. *Dialogues in Clinical Neuroscience*, 11(2):217–28. Retrieved October 25, 2019 from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/>.

Centers for Disease Control and Prevention (**CDC**). (2019). Supporting Caregivers: A Healthy Brain Initiative Issue Map. Alzheimer’s Disease and Healthy Aging Program. Retrieved October 29, 2019 from <https://www.cdc.gov/aging/healthybrain/issue-maps/supporting-caregivers.html> and <https://www.cdc.gov/aging/healthybrain/pdf/Issue-Map-Supporting-Caregivers-508.pdf>

Centers for Disease Control and Prevention (**CDC**). (2019a). Tips for Caregivers. Health Literacy, Older Adults. Retrieved October 29, 2019 from <https://www.cdc.gov/healthliteracy/developmaterials/audiences/olderadults/tipsforcaregivers.html>.

Centers for Disease Control and Prevention (**CDC**). (2019b). Caregiving. Alzheimer’s Disease and Healthy Aging Program. Retrieved October 25, 2019 from <https://www.cdc.gov/aging/caregiving/index.htm>.

Centers for Disease Control and Prevention (**CDC**). (2019c). Caregiving for Person with Alzheimer’s Disease or a Related Dementia. Retrieved October 29, 2019 from <https://www.cdc.gov/aging/caregiving/alzheimer.htm>.

Centers for Disease Control and Prevention (**CDC**). (2019d). Caregiving for Family and Friends—A Public Health Issue. Alzheimer’s Disease and Healthy Aging Program. Retrieved October 29, 2019 from <https://www.cdc.gov/aging/caregiving/caregiver-brief.html>

Centers for Disease Control and Prevention (**CDC**). (2019e). Alzheimer’s Disease and Healthy Aging Data Portal. Retrieved October 22, 2019 from <https://www.cdc.gov/aging/agingdata/index.html>.

Christiansen S. (2019). Study Shows the Effectiveness of Supportive Care Approaches for Dementia. Our Blog, *alzheimers.net*. Retrieved October 27, 2019 from <https://www.alzheimers.net/study-shows-the-effectiveness-of-supportive-care-approaches-for-dementia/>.

Family Caregiver Alliance (**FCA**). (2016). Ch. 1: Transfer Skills (Caregiver College Video Series). Retrieved November 3, 2019 from <https://www.caregiver.org/ch-1-transfer-skills-caregiver-college-video-series>.

Family Caregiver Alliance (**FCA**). (2014). Definitions. Retrieved October 31, 2019 from <https://www.caregiver.org/definitions-0>.

Family Caregiver Alliance (**FCA**). (2012). Alzheimer's Disease and Caregiving. Retrieved October 27, 2019 from <https://www.caregiver.org/alzheimers-disease-caregiving>.

Family Caregiver Alliance (FCA). (2006). Care Givers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers. Retrieved October 24, 2019 from https://www.caregiver.org/sites/caregiver.org/files/pdfs/Assessment_Toolkit_20060802.pdf.

Family Caregiver Alliance (**FCA**). (n.d.). FCA Learning Center. Retrieved November 3, 2019 from <https://www.caregiver.org/caregiver-learning-center>.

Home Alone Alliance. (n.d.). Family Caregiving How-To Video Series. Retrieved November 1, 2019 from <https://www.aarp.org/ppi/initiatives/home-alone-alliance.html>.

Kernisan L. (2019). What Are Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)? *Better Health While Aging: Practical Information for Aging Health and Family Caregivers*. Retrieved November 1, 2019 from <https://betterhealthwhileaging.net/what-are-adls-and-iadls/>.

Kerr N. (2019). Family Caregivers Who Perform Medical Tasks Need More Support: 20 million people face caregiving challenges without training, report finds. AARP Family Caregiving Medical. April 17, 2019. Retrieved November 1, 2019 from <https://www.aarp.org/caregiving/health/info-2019/medical-tasks-study.html>.

Lloyd J, Muers J, Patterson TG, Marczak M. (2018). Self-Compassion, Coping Strategies, and Caregiver Burden in Caregivers of People with Dementia. *Clinical Gerontologist* 42, no. 1 (2019). Retrieved October 27, 2019 from <https://www.tandfonline.com/doi/full/10.1080/07317115.2018.1461162>.

Mayo Clinic. (2018). <https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784>.

Mayo Clinic. (2017). Relaxation techniques: Try These Steps to Reduce Stress. Retrieved November 4, 2019 from <https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/relaxation-technique/art-20045368?pg=2>.

Medicare.gov (n.d.). PACE. Retrieved October 25, 2019 from <https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/pace>.

Medicare.gov (2017). Quick Facts about Programs of All-Inclusive Care for the Elderly (PACE). Retrieved October 25, 2019 from <https://www.medicare.gov/sites/default/files/2018-07/11341-pace.pdf>.

Michigan Medicine, University of Michigan. (2017). "Pop drop" study finds more ER visits, higher costs for older disabled patients. Retrieved October 31, 2019 from <https://www.sciencedaily.com/releases/2017/08/170824090105.htm>.

Next Step in Care. (2015). For Family Caregivers: Medication Management. Guide/Form/Videos. Retrieved October 31, 2019 from https://www.nextstepincare.org/Caregiver_Home/Medication_Management_Guide/.

Next Step in Care. (2012). A Toolkit for Working with Family Caregivers. Retrieved November 4, 2019 from <https://www.nextstepincare.org/providers/toolkit/>.

Next Step in Care. (n.d.) Videos. Retrieved November 1, 2019 from <https://www.nextstepincare.org/Videos/>.

Reinhard SC, Levine C, Samis S. (2019). Home Alone Revisited: Family Caregivers Providing Complex Care. Founders of the Home Alone Alliance. Retrieved November 1, 2019 from <https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>.

Reinhard SC, Given B, Petlick NH, Bemis A. (2008). Supporting Family Caregivers in Providing Care. In Hughes RG, ed. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Agency for Healthcare Research and Quality. Retrieved October 25, 2019 from: <https://www.ncbi.nlm.nih.gov/books/NBK2665/>.

Robinson L, Wayne MS, Segal J. (2019). Tips for Alzheimer's & Dementia Caregivers. HelpGuide. Retrieved October 28, 2019 from <https://www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm>.

Sauer A. (2019). The Reasons Why Alzheimer's and Dementia Caregivers Are So Stressed. Our Blog, alzheimers.net. Retrieved October 27, 2019 from <https://www.alzheimers.net/the-reasons-why-alzheimers-and-dementia-caregivers-are-so-stressed/>.

Slaboda J, Fail R, Norman G, Meier DE. (2018). *A Study of Family Caregiver Burden and the Imperative of Practice Change to Address Family Caregivers' Unmet Needs*. Health Affairs Blog. January 11, 2018. DOI: 10.1377/hblog20180105.914873.

University of Michigan's Institute of Gerontology & the National Association of Chronic Disease Directors. (2009). Implementing a Community-Based Program for Dementia Caregivers: An Action Guide using REACH OUT. National Association of Chronic Disease Directors, Atlanta, GA. https://cdn.ymaws.com/www.chronicdisease.org/resource/resmgr/Healthy_Aging_Critical_Issues_Brief/ReachOutActionGuide.pdf.

von Känel R., Mausbach BT, Dimsdale JE et al. (2019). Refining caregiver vulnerability for clinical practice: determinants of self-rated health in spousal dementia caregivers. *BMC Geriatrics* 19(18). Doi:10.1186/s12877-019-1033-2. Retrieved October 25, 2019 from <https://bmgeriatr.biomedcentral.com/articles/10.1186/s12877-019-1033-2#citeas>.

White CL, Overbaugh KJ, Pickering CEZ, Piernik-Yoder B, et al. (2018). Advancing care for family caregivers of persons with dementia through caregiver and community partnerships. *Research Involvement and Engagement* 4(1). Retrieved October 22, 2019 from <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0084-4>.

Post Test

1. Caregivers for patients with Alzheimer's disease and other dementias can include:

- a. Formal and informal (family) caregivers.
- b. Only formal caregivers working for an agency.
- c. Only informal (family) caregivers
- d. Only healthcare providers.

2. Supporting caregivers is a public health concern because:

- a. The burden is large, the impact major, and intervention is impossible.
- b. The burden is large, the impact major, and intervention is possible.
- c. The burden is small, the impact major, and intervention is possible.
- d. The burden is large, the impact minor, and intervention is possible.

3. A fundamental challenge for healthcare providers working with dementia patients and their caregivers is:

- a. Care cannot be discussed with anyone but the patient.
- b. Caregivers are all the same and generally have negative motivations.
- c. The provider may at times feel they have "2 patients."
- d. Dementia patients never know who their caregivers are.

4. Research has shown the caregivers:

- a. Are a monolithic group and similar across demographic variables.
- b. Differ based on generations only.
- c. Differ based on gender only.
- d. Are a diverse group with different experiences across many variables.

5. Categories of care are:

- a. ADLs, IADLs, and M/Ns.
- b. Only Medical/Nursing tasks (M/Ns).
- c. ADLs and IADLs only.
- d. Only IADLs

6. Caregivers do not like educational videos for receiving training.

- a. True

b. False

7. Caregivers consider healthcare providers to be:

- a. Poor sources of information.
- b. Too busy to help.
- c. Trusted sources of information.
- d. Resources of last resort.

8. Care plans:

- a. Are not really necessary or useful.
- b. Made up as you go.
- c. Are really only beneficial for caregivers.
- d. Are beneficial to care recipients, caregivers, and healthcare providers.

9. The most common medical/nursing task caregivers perform is:

- a. Medication management.
- b. Help with assistive devices for mobility.
- c. Special meals.
- d. Wound care.

10. The CARE Act:

- a. Has been made law in all 50 states.
- b. Is intended to recognize caregivers as part of a patient's overall health team.
- c. Has been resisted in most states.
- d. Has received 100% compliance.

11. Caregiver Assessments:

- a. Are just another kind of care plan.
- b. Evaluates the care recipient and what they need from the caregiver.
- c. Build caregiver morale and capacity and are key to care planning.
- d. Are only used to establish eligibility for outside services.

12. Stress is a serious and common issue for family caregivers and it can affect mental and physical health.

- a. True
- B. False

Answer Sheet

Dementia: Supporting Caregivers

Name (Print) _____

Date _____

Passing score is 80%

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

11. _____

12. _____

Evaluation: Dementia: Supporting Caregivers

Upon completion of the course, I was able to:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
State 3 reasons why caregiver support is a public health concern.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
List 4 challenge for healthcare providers working with dementia care recipients and their caregivers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Name 5 ways you can support caregivers who are caring for patients with Alzheimer's disease and other dementias.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Name 6 risks for caregivers as they are providing support for people who have dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rate the following statements:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The author(s) are knowledgeable about the subject matter.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The author(s) cited evidence that supported the material presented.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please answer Yes or No to these statements:

	Yes	No
Was this course contained no discriminatory or prejudicial language?	<input type="radio"/>	<input type="radio"/>
Was the course was free of commercial bias and product promotion?	<input type="radio"/>	<input type="radio"/>
As a result of what you have learned, do you intend to make any changes in your practice?	<input type="radio"/>	<input type="radio"/>

If you answered Yes above, what changes do you intend to make? If you answered No, please explain why.

Do you intend to return to ATrain for your ongoing CE needs?

- Yes, within the next 30 days.
- Yes, during my next renewal cycle.
- Maybe, not sure.
- No, I only needed this one course.

Navigating the ATrain Education website was:

- Easy.
- Somewhat easy.
- Not at all easy.

Would you recommend ATrain Education to a friend, co-worker, or colleague?

- Yes, definitely.
- Possibly.
- No, not at this time.

What is your overall satisfaction with this learning activity?

- Very satisfied
- Satisfied
- Neutral
- Dissatisfied
- Very dissatisfied

How long did it take you to complete this course, posttest, and course evaluation?

- 60 minutes (or more) per contact hour
- 50–59 minutes per contact hour
- 40–49 minutes per contact hour
- 30–39 minutes per contact hour
- Less than 30 minutes per contact hour

I heard about ATrain Education from:

- Government or Department of Health website
- State board or professional association
- Searching the Internet
- A friend
- An advertisement
- I am a returning customer
- My employer
- Social Media (FB, Twitter, LinkedIn, etc)
- Other...

Registration and Payment Form

Please answer all of the following questions (* required).

*Name: _____

*Email: _____

*Address: _____

*City and State: _____

*Zip: _____

*Country: _____

*Phone: _____

*Professional Credentials/Designations:

*License Number and State: _____

*Name and credentials as you want them to appear on your certificate.

Payment Options

You may pay by credit card, check or money order.

Fill out this section only if you are paying by credit card.

1.5 contact hours: \$19

Credit card information

*Name: _____

Address (if different from above):

*City and State: _____

*Zip: _____

*Card type: Visa Master Card American Express Discover

*Card number: _____

*CVS#: _____ *Expiration date: _____