

CARING FOR THE DEMENTIA CAREGIVER



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GRECC CONNECT - CASE CONFERENCE SERIES

- ▶ **GRECC Connect Program (GC)** delivers virtual geriatric consultation with the aim to improve access to geriatric care for Veterans in rural areas. This project links geriatrics specialists from GRECCs (Geriatric Research, Education and Clinical Centers), located in urban tertiary medical centers, to providers and patients in rural areas. Clinical video telehealth, electronic consultation, and educational teleconferences bridge communication and access gaps that rural populations face.
- ▶ Through this project, we aim to equip rural providers and staff with the knowledge and skills to care for older adults. GC supports staff at rural clinics.
- ▶ Funded by the VA Office of Rural Health (ORH)



DISCLAIMERS:

- ▶ The views expressed in this presentation are those of the author(s) and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States Government.
- ▶ Reference herein to any specific commercial products, process, or service by trade name, trademark, manufacturer, or otherwise, does not necessarily constitute or imply its endorsement, recommendation, or favoring by the United States Government.

BACKGROUND

- ▶ Working with dementia caregivers
- ▶ Practice concepts that can be used by providers and applied to dementia caregiver work for Veterans, including rural Veterans

OUTLINE

- **Overview**
- **Build a care team**
- **Sustain the relationship**
- **Manage problems**
- **Plan for the future**



JOAN

- 47 year old married working mother of two (11, 7)
- Administrative assistant to a large medical practice
- Primary caregiver for her father with AD diagnosed 4 years prior
- Presents with cognitive decline, becomes confused about who she is at some visits, repetitive, difficult to get out of bed on occasion, she worries he is depressed, refuses daycare, she has concerns about guns in his home
- Lives 20 minutes from her father's house, tries to visit daily
- Helps with medication management (pillbox and reminders, grocery shopping, appointments, finances)
- Parents divorced when she was 7
- Father is a combat Veteran with a history of PTSD, depression, and alcohol abuse; 1 prior suicide attempt
- Father was abusive when she was younger
- Largely absent throughout her childhood following the divorce
- Reengaged when she was in college after he became sober
- She has an older brother that lives several states away and is not involved in their father's care



DONALD

- 82 year old former Army Veteran
- Married 56 years to his “soul mate”
- Two adult children that live out of state
- Primary caregiver for wife diagnosed with AD 9 years ago
- Wife has cognitive decline, personality changes – is aggressive and “mean”, significant weight gain, declines in self care, combative around medications and baths
- Sadness over loss of their relationship, cannot do activities they used to enjoy together
- He has a history of PTSD and depression, has been in treatment in the past, not in the last 15 years, found treatment helpful, endorses current depressed mood
- Visiting nurse comes to the home 4 times a week to help his wife dress and bathe, do some light housework
- Children have urged him to consider a higher level of care outside the home; he is very reluctant to do that

OUTLINE

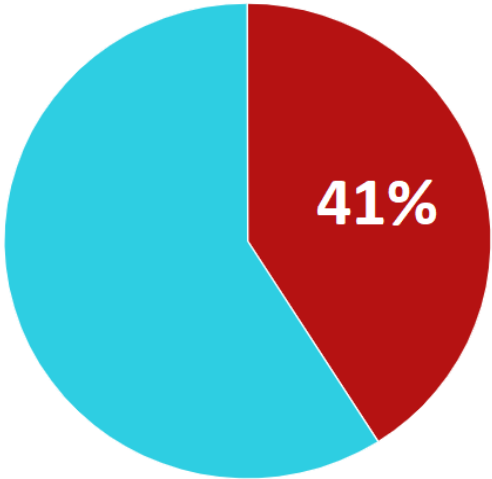
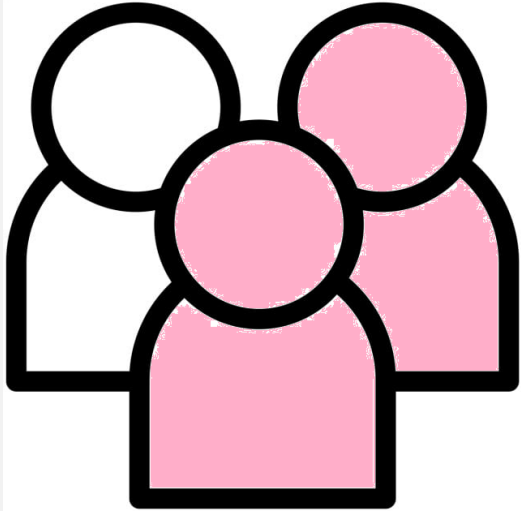
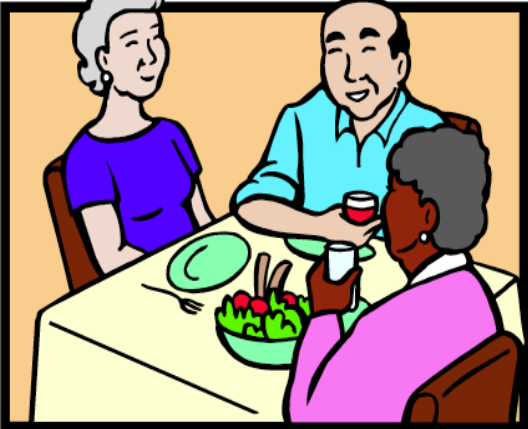
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A DISEASE OF FAMILIES

- 83% of help provided to older adults in the US comes from **informal, untrained, unpaid** caregivers (family and friends)
- In 2017, these caregivers provided an estimated 16 billion hours of informal, unpaid care (**27.1 hours per CG/per WK**) valued at \$271.6 billion in 2021 (higher than the 2021 annual revenue of Google)
- Three primary reasons caregivers provide care:
 - Desire to keep individual with dementia at home (65% seniors want to age in place)
 - Desire to remain close to the individual with dementia
 - Perceived obligation



WHO ARE THEY?



alzheimer's  association®

PARENT'S GUIDE

HELPING CHILDREN AND TEENS
UNDERSTAND ALZHEIMER'S DISEASE

FINANCIAL BURDEN

Of the total lifetime cost of caring for someone with dementia, 70% is born by families

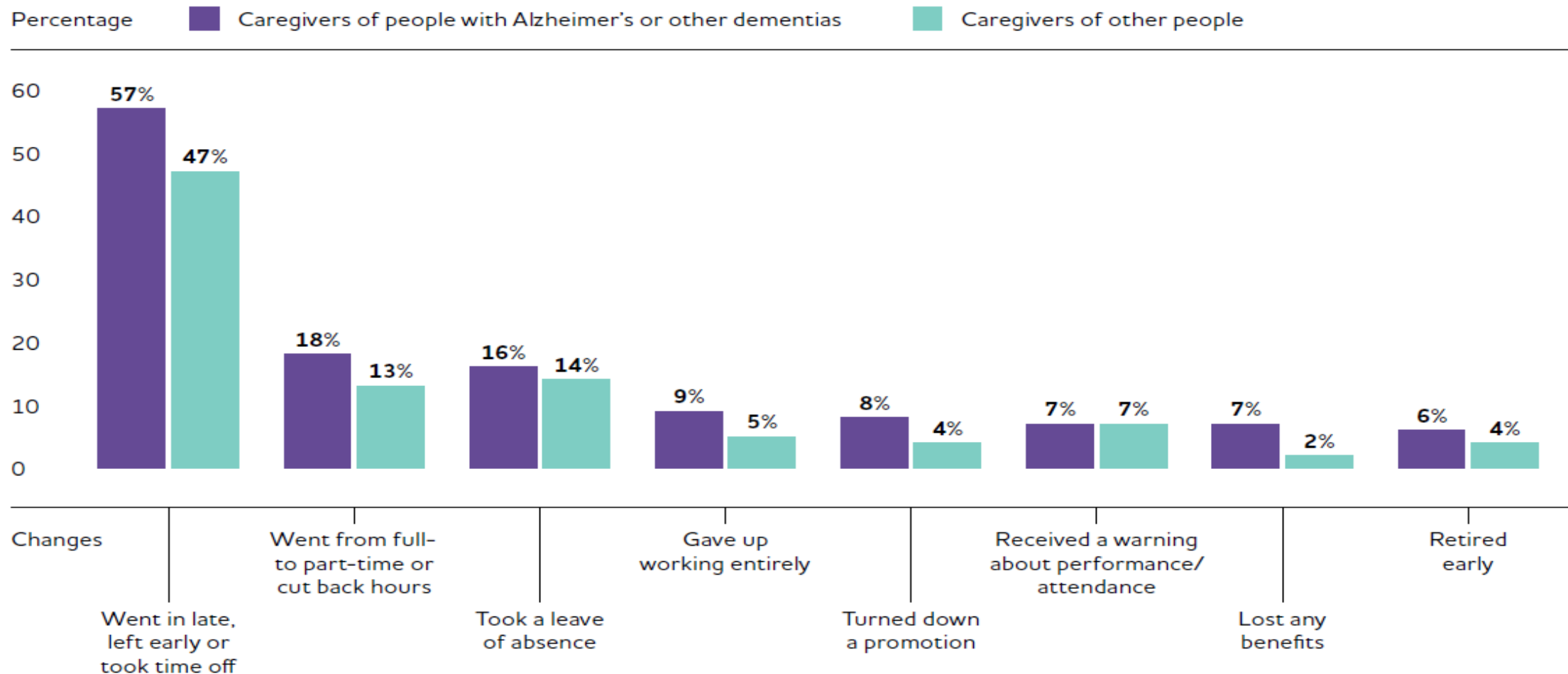
48% cut back on spending, 43% cut back on savings due to costs

40% caregivers say the food they bought didn't last and they didn't have money to get more

30% said they ate less because of care-related costs

FIGURE 9

Work-Related Changes Among Caregivers of People with Alzheimer's or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving



Created from data from the National Alliance for Caregiving and AARP.²⁶⁸

WHAT DO CAREGIVERS DO?

- **“Whatever it takes”**
- Includes help with:
 - activities of daily living
 - physical care
 - symptom management
 - emotional support
- Includes support while care recipient is in a facility

CONSEQUENCES OF CAREGIVING

Physical

74% somewhat to very concerned about maintaining their own health

27% delayed or did not do things for their own health

35% report their health has gotten worse due to care responsibilities

Emotional

60% High/Very High stress

30-40% Depression

44% Anxiety

THE CAREGIVING CAREER

- Transition from the beginning of thinking of oneself as a caregiver to the end of that role
- Defining oneself as a “caregiver” differs from person to person
- Many changes occur over the “caregiving career” as caregivers continually redefine their role in response to a progressive and changing illness
- “Career” comes to a close with the passing of the loved one
- Which itself requires another transition

CAREGIVING AND COVID

- Quarantine decreases CG mental health and well-being, increases burden
- Quarantine increases NPS, decreases cognitive functioning and physical functioning [direct and indirect hypotheses]
- Patients differ in awareness by disease severity and lack of awareness if a concern for CGs; total awareness seems may be a protective factor for cognitive decline
- Greater dementia severity and functional dependence risk for greater negative consequences for CGs
- Lower CG resilience risk for greater negative consequences for CGs
- Loss of services, care, and support are big issues for CGs

CAREGIVING AND COVID

- Higher CG education may be protective [ass'd w occupation, job loss, etc. not explored or mentioned]
- Living with someone else was protective in one study, decreased conflicts with PWD [we can also see how it may not be if increased family conflicts]
- Male gender may be protective [seems to jive with CG gender research more broadly]
- Acknowledged need for solutions, many technology based, CGs say technology based care helps, CGs seem to want technology, flip side is concerns for technology esp. for the PWD, seems like even contact only and tips [Cuffaro et al, Dementia care and COVID-19 Pandemic: **a necessary digital revolution**]
- CGs report long term needs post-pandemic, including CG education and training

**TELEHEALTH SUPPORT FOR DEMENTIA CAREGIVERS DURING THE COVID-19 PANDEMIC: LESSONS
LEARNED FROM THE NYU FAMILY SUPPORT PROGRAM**

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- N=10, all NYC, spouses living with PWD
- May-June 2020, 7 female, 9 white, 9 heterosexual
- Themes:
 - **Changes in level of support**
 - **Changes in the relationship with the PWD**
 - **CGing stress due to differences in pandemic perception**
 - **Benefits and silver linings**
 - **Use of telehealth modality**

BEDFORD VA DEMENTIA CAREGIVER SERVICES

Individual dementia caregiver support (in person or via video):

You will meet individually with an assigned caregiver support specialist. The initial session will focus on better understanding your situation and creating a plan to maximize your support. Caregivers needs vary and individual support can be used as a place to get emotional support, gain knowledge about dementia (What is Alzheimer's disease? What kinds of things can I expect over the course of the disease?), and/or learn specific and targeted caregiving skills (How do I reduce problem behaviors? How do I keep my loved one engaged in the world?). The support you receive will be tailored to meet your needs and can be as short as 1 session or can be multiple sessions.

Dementia Caregiving 101 (video class):

Dementia Caregiving 101 is a 10-week class for one hour a week that aims to (1) teach you what dementia is (2) provide techniques and tips to help you manage common problems in individuals with dementia (3) explain how you can build a care team to help you manage caregiving demands, and (4) show you how to manage your wellbeing while providing care to your loved one. Class instructors are clinicians with expertise in dementia diagnosis and management. New 10-week classes start quarterly.

Dementia Caregivers Support Group (video group):

The dementia caregivers support group is a weekly group that runs an hour a week and is designed to be a place where you can engage in less formal discussion about the ups and downs of caring for someone with dementia. The group offers a place to gain support from other dementia caregivers. It is facilitated by a staff member with expertise in dementia. The group runs in 8-week cycles, accepting new members every 8 weeks. Members can remain in the group for as long as they wish.

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BUILDING A CARE TEAM

- **Starts with the caregiver! No-one can provide care alone –Ask for help!!!!**

CARING FOR ONESELF



YOU CAN'T POUR
FROM AN EMPTY CUP.

HOW DO OUR CGS “FILL THEIR CUPS”?



Staying healthy

Diet, exercise, sleep, medical care



Making time for themselves

“me time”, enjoyable activities, socializing, cultivating gratitude



Managing emotions

Listen, in-office screens, refer as needed



Finding support

It takes a village, the concept of a care team

BUILDING A CARE TEAM

- Starts with the caregiver! No-one can provide care alone –Ask for help!!!!
- It is a partnership between patient, caregiver, and treating providers, but also others!
- Getting family members and significant others on the same page
- Family and friends – make a list, discuss tasks – how can people help, be explicit, have a plan, even small tasks – picking up medications, mowing the lawn, going for a walk
- Enlist neighbors – extra pair of eyes, maybe they can visit, do errands around town, watch locally and intervene, if caring from afar – can they check in
- Support groups
- Professional caregivers – geriatric care managers (aging life care association), visiting nurses (monitoring vital signs, caring for wounds, administering medications), home health aids (bathing, help with toileting, cleaning, food prep) , volunteers (seniors helping seniors, buddy programs)
- National and community organizations

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CARING FOR EACH OTHER



SUSTAINING RELATIONSHIPS

- Relationships change
- Do enjoyable things together:
 - Take into account changing abilities and interests
 - Take the lead
 - Plan ahead
 - Start small
 - Consider time of day
 - Go with the flow
 - Be in the moment
 - Don't give up
 - **Permission to stay home**

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4 RS:
REASSURE, RECONSIDER, REDIRECT, RELAX

- **Reassure** them that everything is OK
- **Reconsider** things from their point of view
- **Redirect** them to another activity
- **Relax** what we must do to avoid escalating the situation



THREETIME PRINCIPLES

- Take your **time**
- One thing at a **time**
- Offer **timely** praise





THE ABCS

Antecedents

(Include the date, time of day, place, person[s] present, and events)

Sunday, 3 PM

Me & my loved one

Bath time

Behavior

(specific, observable, measurable—frequency and/or duration)

Yelling for 7 minutes

Consequence

(How did things change?)

Decided to skip the bath that day

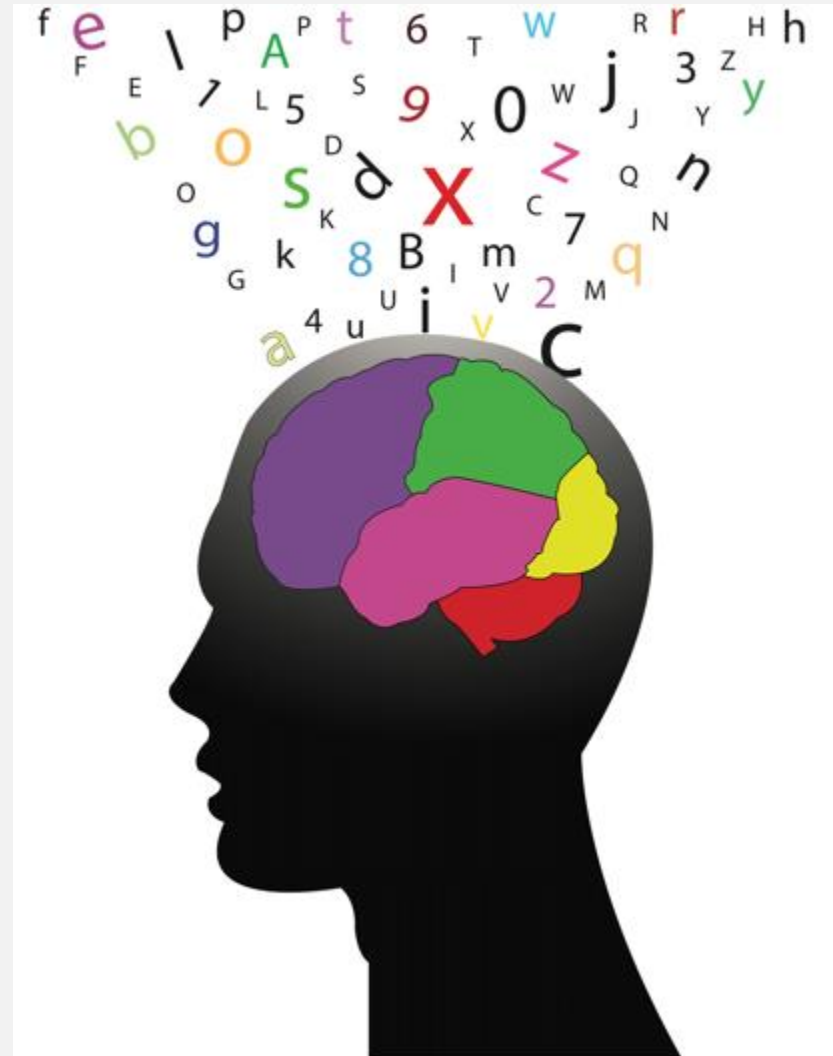
MANAGE MEMORY PROBLEMS

- Discuss memory aids for mildly impaired individuals
- Eliminate wandering
 - STOP sign, lock doors, alarm
 - Identification jewelry, tracking devices
 - **Make a plan for wandering**
- **Don't fight false memories—go with them!**
- Reminding people of their memory problems is rarely helpful



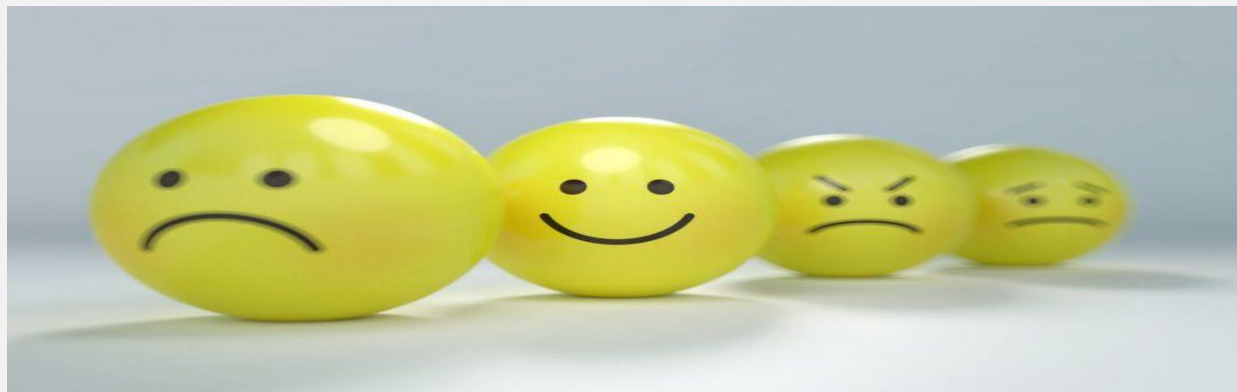
MANAGE LANGUAGE PROBLEMS

- Difficulties with word finding and comprehension
- Check hearing
- Use pictures
- Non-verbal & emotional communication often preserved



MANAGE EMOTIONAL PROBLEMS

- Look for and treat anxiety and depression.
- Look for and provide education about apathy



MANAGE DRIVING

- Patients with very mild AD have accident rates similar to 16-to-19-year-old drivers.
- Should we let these patients drive?
- Family member to ride as passenger monthly.
 - If family members are comfortable riding with patient driving, then patient may be OK to drive.
 - Family member to ride as passenger monthly.
 - Adult children are best. (Am J OT 2015 69: 6903270030)
- Driving evaluation is the gold standard – might be able to be done at VA
- Hartford Foundation and MIT AgeLab resources
 - Family Conversations with Older Drivers
 - A Guide to Comprehensive Driving Evaluation
 - Free brochures for your office
 - thehartford.com/resources/mature-market-excellence/about-us



OTHER SAFETY CONCERNS

- **Guns**
- **Power tools**
- **Kitchen safety (knives, appliances, stove)**
- Remove offending items, remove knobs, from stove, use childproof and other locks
- Abusive/threatening behavior:
 - Manage with learned techniques, soothing music, distraction, etc.
 - Call family, friends, or the police
 - Get out of the house



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PLAN FOR THE FUTURE

- Families should be encouraged to include the individual as much as possible
- Conversations are best had early
- Decisions about where to live
- Decisions about driving
- Financial and legal planning
- Decisions about end of life
 - Who will be there?
 - What is a good death?
 - Consider brain donation
 - The ceremony
- Planning for the future of the caregiver

PLAN FOR THE FUTURE

- Often difficult for families
- **Plan early and involve the person with dementia**
- **Take care of medical/legal issues**
 - Living will
 - Healthcare proxy
 - Do Not Resuscitate

PLAN FOR THE FUTURE (CONTINUED)

- **Take care of financial/legal issues**
 - Will
 - Estate planning
 - Power of attorney
 - Trusts
- **Protect your loved one from scams, con artists, and poor judgment**
- **Refer patients and families to**
 - Elder care attorneys
 - Social workers
 - Geriatricians

PLAN FOR THE FUTURE (CONTINUED)

- **Housing**
 - Helping families navigate the question “When is it time?”
 - Ultimately, it is a personal decision, and every family is different
 - Some guidelines to help family members reflect, with a focus on safety of self and others:

GUIDELINES TO HELP FAMILY MEMBERS REFLECT

- Does your loved one leave the stove on?
- Is wandering a problem?
- Has there been an increase in falls, accidents, mobility needs (transfers, assistance walking)?
- Are there problems with medication management?
- Is physical violence and aggression a problem?
- Has there been increasing incontinence?
- Is the home unclean? Are there sanitary issues? Do you notice spoiled food?
- Is your loved ones diet poor? Are there struggles with meeting nutritional needs?
- Does your loved one lack social stimulation, cognitive stimulation? Are they lonely?
- Do you feel resentment and burnout?

PLAN FOR THE FUTURE (CONTINUED)

- **Housing options**
 - Assisted living
 - Nursing homes
 - Continuing care retirement communities
- **Making the transition**
 - Ease into new housing slowly

PLAN FOR THE FUTURE (CONTINUED)

- **Talking about death and dying**
- **The ceremony**
- **The death itself**
 - **Hospice & palliative care**
- **Dying from dementia**
- To be there or not at the end
- The body
 - Consider brain donation in the context of ongoing research
- The grieving process and your emotional health
- **Helping the caregiver plan for their future**

IT TAKES A VILLAGE

Financial and Legal Resources






- Administration on Aging (aoa.gov)
- Area Agency on Aging (n4a.org or 800-677-1116 for local agency)
- Family Caregiver Alliance (caregiver.org)
- Eldercare Locator (eldercare.gov)
- National Academy of Elder Law Attorneys (naela.org)
- Medicare Right (medicarerights.org)
- National Hospice and Palliative Care Organization (nhpco.org)
- Nursing Homes (medicare.gov/nhcompare)

PGCSS General Caregivers

Caregivers within PGCSS are recognized as **General Caregivers**. A General Caregiver is a person who provides personal care services to a Veteran enrolled in VA health care who:

- Needs assistance with one or more activities of daily living **or**
- Needs supervision or protection based on symptoms or residuals of neurological impairment or other impairment or injury.

PGCSS General Caregivers may have access to:

-  Training and support through in-person, online, and telehealth sessions.
-  Skills training focused on caregiving for a Veteran's unique needs.
-  Individual counseling related to the care of the Veteran.
-  Respite care, a resource that offers medically and age-appropriate short-term services to eligible Veterans and allows caregivers to take time for themselves. In contrast, the Veteran is cared for in a safe and caring environment
-  Peer Support Mentoring.

More information about the services listed above can be found on pages 3-5.

There is no formal application required to enroll in PGCSS. To enroll, complete the following steps:

1. Reach out to the facility [CSP Team/Caregiver Support Coordinator](#) or request a referral from the Veteran's provider.
2. Complete an intake with the facility [CSP Team/Caregiver Support Coordinator](#). The Veteran will need to agree to receive care from you as their caregiver, as you will be listed in their healthcare record.
3. Enroll and begin to utilize the supports and services offered.

- [PGCSS Fact Sheet - English \(PDF\)](#)
- [PGCSS FAQs Flyer - English \(PDF\)](#)
- [Hoja de datos de PGCSS - Spanish \(PDF\)](#)
- [Folleto de preguntas frecuentes sobre PGCSS - Spanish \(PDF\)](#)
- [PGCSS factsheet - Tagalog/Filipino \(PDF\)](#)
- [Flyer ng Mga FAQ ng PGCSS - Tagalog/Filipino \(PDF\)](#)

What services does this program offer?

Veterans can designate one (1) Primary Family Caregiver and up to two (2) Secondary Family Caregivers on the application. Secondary Family Caregivers serve as a backup support to the Primary Family Caregiver when needed. Services will depend on whether you are the Primary Family Caregiver or a Secondary Family Caregiver.

If you are the primary caregiver, you may receive:

- A monthly stipend (paid directly to you as the caregiver.)
- Access to health care insurance through Civilian Health and Medical Program of the Department of Veterans Affairs (**CHAMPVA**), if you do not already have health insurance.
- Mental health counseling.
- Certain **beneficiary travel benefits** when traveling with the Veteran to appointments. For specific details, please contact your **CSP Team**.
- At least 30 days of respite care per year, for the Veteran. **Respite** is short term relief for someone else to care for the Veteran while you take a break.

If you are the secondary caregiver, you may receive:

- Mental health counseling.
- Certain beneficiary travel benefits when traveling with the Veteran to appointments. For specific details, please contact your local **CSP Team**.

Be sure to check www.caregiver.va.gov for updates or [subscribe](#) to receive email updates and information about VA Caregiver Support Program services.

IT TAKES A VILLAGE

- VA Caregiver Support Program: <https://www.caregiver.va.gov/>
- Program of General Caregiver Support Services (PGCSS)
- Program of Comprehensive Family Assistance for Family Caregivers

Veterans Transportation Service Locations

The Veterans Transportation Service (VTS) is designed to ensure that all qualifying Veterans have access to care through convenient, safe, and reliable transportation. VTS provides qualifying Veterans with free transportation services to and/or from participating VA medical centers (VAMCs) in a multi-passenger van. This service ensures that all qualifying Veterans who do not have access to transportation options of their own, due to financial, medical, or other reasons, are able to travel to VA medical facilities or authorized non-VA appointments to receive the care they have earned. Please click on your state to see a listing of VTS sites and Points of Contact in your area to assist you in meeting your transportation needs.

Select by State

Select a state or territory below to view a list of participating VA medical centers in your area.

Alabama

Alaska

Caregiver Video Series:

- Improving Communication in Dementia
- Intimacy in Dementia
- Safety Risk in Dementia
- Preventing Financial Mismanagement
- Minimizing Inappropriate Behavior
- Engaging People with Dementia in Meaningful Activities
- Managing Behaviors using the ABCs
- Information about home safety, legal matters, relaxation techniques
- Managing wandering
- Choosing a Nursing Facility

IT TAKES A VILLAGE

- Office of Rural Health: <https://www.ruralhealth.va.gov/vets/resources.asp#support>
- VA Caregiver Support Line 1-855-260-3274; learn about resources, get support, staffed by SW
- Veterans Transportation Services, state by state contact info
- Caregiver Video Series, various topics

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WHAT THIS SURVIVAL GUIDE IS FOR:

This guide is intended to help family members care for a Veteran with dementia. The strategies and information included in this guide can be applied no matter where you live, no matter what stage of dementia the Veteran has, and no matter what resources are available near you.

May these pages help support you along your caregiving journey.

IT TAKES A VILLAGE

- Gerischolars Website: <https://www.gerischolars.org/mod/page/view.php?id=20> online learning tools for professionals and families
- Dementia Caregiver Survival Guide: Tips for Caring for a Veteran with Dementia
https://www.gerischolars.org/pluginfile.php/9034/mod_page/content/7/VA%20Survival%20Guide_508.pdf
- Table of Contents Examples: Understanding Dementia, Communication Tips, Managing Difficult Behaviors, Self Care, Managing and Honoring Grief

Daily Activities



The daily activities section provides resources for challenges with common activities.

- Activities of Daily Living (Grooming/Bathing/Dressing etc.)
- Medication
- Dementia and Activity Participation
- Traveling
- Driving
- Sex and Intimacy
- Sleep
- Nutrition

Safety



Keeping a
This section
community

- Home Safety
- Firearm Safety
- Falls Prevention
- Emergency Preparedness

Websites

- VA Office of Rural Health
- VA Geriatrics and Extended Care
- VA Caregiver Support Program
- VA Benefits For Spouses, Dependents, Survivors and Family Caregivers
- VA Telehealth Services
- VISN 2 GRECC Caregiver Support Project
- Alzheimer's Association
- National Institute on Aging (NIA)
- Dementia Care Central (funded by NIA)
- Family Caregiver Alliance
- American Association of Retired People (AARP)

IT TAKES A VILLAGE

- Gerischolars Website: <https://www.gerischolars.org/mod/page/view.php?id=20> online learning tools for professionals and families
- Learning materials for dementia caregivers
- Links to additional VA and non VA resources

November is National Family Caregivers Month

Join us as we honor the millions of caregivers for their dedication, generosity and strength in the battle against Alzheimer's.

The Alzheimer's Association 24/7 Helpline (800.272.3900) is available around the clock, 365 days a year. Through this free service, specialists and master's-level clinicians offer confidential support and information to people living with dementia, caregivers, families and the public.



The Holidays and Alzheimer's

The holidays can be challenging for families living with Alzheimer's or another dementia. With some planning and adjusted expectations, your celebrations can be happy, fulfilling occasions.

IT TAKES A VILLAGE

- Alzheimer's Association
- Numerous Resources
- Support Groups – online, in-person
- 24/7 Helpline 800-272-3900
- Ways families can get involved: funding raising events, advocacy, volunteering [MEANING AND PURPOSE]



- Individual support focused on the impact of the past relationship on caregiving – feelings of resentment, guilt, sadness – “old wounds”; made a plan for self-care “filling her cup”
- Resources to supplement care and reduce burden of balancing caring for her family and her father
 - Building a care team with other Veterans (friend)
 - Grocery delivery services
 - Books/resources for kids
 - Referred to social work for help establishing home health services for medication management and additional assistance with ADLs (light housework)
- Education about apathy, father not endorsing sadness, pleasant activities scheduling, old photos, use of music
- Plans to remove guns from the home
- Connected her to the Alzheimer’s Association – engaged in a support group for adult child caregivers
- Provided links to VA Caregiver Video Series and Dementia Caregiver Survival Guide
- Referred to VA Caregiver Support Program to assess eligibility for monthly stipend, respite care, other services
- Joined our Caregiver Toolbox class



Individual support focused on profound loss of relationship with wife

- Referred to our mental health clinic for additional emotional support (prior PTSD, depression)
- Introduced the 4 Rs and engaged in focused practice outside sessions
- Discussed futility of challenging false claims → resulting combativeness; processed feelings related to dishonesty
- Applied music and singing to assist with bathing
- Implemented pleasant activities scheduling to replace activities they used to enjoy together – sorting cards, holding hands
- Discussed and honored fears of moving his wife to a higher level of care, – past bad experiences with his father and belief she will die if he moves her
- Reviewed content that might help him to reconsider a move – “how will I know when it’s time?”
- Provided resources for Alzheimer’s Association – joined online mens support group
- Also referred him to TeleCARE program (research-based intervention study) for additional, focused skills training in a group context

QUESTIONS

