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.

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

<table>
<thead>
<tr>
<th>Changes</th>
<th>Caregivers of people with Alzheimer's or other dementias</th>
<th>Caregivers of other people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Went in late, left early or took time off</td>
<td>57%</td>
<td>47%</td>
</tr>
<tr>
<td>Went from full- to part-time or cut back hours</td>
<td>18%</td>
<td>13%</td>
</tr>
<tr>
<td>Took a leave of absence</td>
<td>16%</td>
<td>14%</td>
</tr>
<tr>
<td>Gave up working entirely</td>
<td>9%</td>
<td>5%</td>
</tr>
<tr>
<td>Turned down a promotion</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td>Received a warning about performance/attendance</td>
<td>7%</td>
<td>7%</td>
</tr>
<tr>
<td>Lost any benefits</td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>Retired early</td>
<td>6%</td>
<td>4%</td>
</tr>
</tbody>
</table>

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
• 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
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.
OUTLINE

• Overview
• **Build a care team**
• Sustain the relationship
• Manage problems
• Plan for the future
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”?

<table>
<thead>
<tr>
<th>Staying healthy</th>
<th>Making time for themselves</th>
<th>Managing emotions</th>
<th>Finding support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet, exercise, sleep, medical care</td>
<td>“me time”, enjoyable activities, socializing, cultivating gratitude</td>
<td>Listen, in-office screens, refer as needed</td>
<td>It takes a village, the concept of a care team</td>
</tr>
</tbody>
</table>
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
• Overview
• Build a care team
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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
• Overview
• Build a care team
• Sustain the relationship
• Manage problems
• Plan for the future
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
THREE TIME PRINCIPLES

• Take your **time**

• One thing at a **time**

• Offer **timely** praise
**THE ABCS**

<table>
<thead>
<tr>
<th>Antecedents</th>
<th>Behavior</th>
<th>Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Include the date, time of day, place, person[s] present, and events</em>&lt;br&gt;<strong>Sunday, 3 PM</strong>&lt;br&gt;<strong>Me &amp; my loved one</strong>&lt;br&gt;<strong>Bath time</strong></td>
<td><em>Specific, observable, measurable—frequency and/or duration</em>&lt;br&gt;<strong>Yelling for 7 minutes</strong></td>
<td><em>How did things change?</em>&lt;br&gt;<strong>Decided to skip the bath that day</strong></td>
</tr>
</tbody>
</table>
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.
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
OUTLINE

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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
• 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
• **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 one’s 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?
Housing options
- Assisted living
- Nursing homes
- Continuing care retirement communities

Making the transition
- Ease into new housing slowly
• 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
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)
IT TAKES A VILLAGE

- VA Caregiver Support Program: [https://www.caregiver.va.gov/](https://www.caregiver.va.gov/)
- Program of General Caregiver Support Services (PGCSS)
- Program of Comprehensive Family Assistance for Family Caregivers
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
Gerischolars Website: [https://www.gerischolars.org/mod/page/view.php?id=20](https://www.gerischolars.org/mod/page/view.php?id=20) online learning tools for professionals and families


Table of Contents Examples: Understanding Dementia, Communication Tips, Managing Difficult Behaviors, Self Care, Managing and Honoring Grief
IT TAKES A VILLAGE

- Gerischolars Website: [https://www.gerischolars.org/mod/page/view.php?id=20](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 \(\rightarrow\) 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