

# Best Practices for Caregiver Support with Dementia Care



Sara Tompkison, LCSW  
Geriatric Workforce Enhancement Program(GWEP Social Work Instructor  
John A. Burns School Medicine – Geriatric Medicine  
Teepa Snow – Positive Approach to Care (PAC) Dementia Educator

Demographic slides courtesy of Drs. Shari Kogan & Kamal Masaki  
John A. Burns School of Medicine – Geriatrics Department

# Learning Objectives:

- Describe three risk factors that can contribute to caregiver burden.
- Explain the purpose of the Zarit Burden Scale and describe best practices and/or therapeutic strategies for managing caregiver burden.
- Identify one best practice and/or approach to improve caregiver health, emotional well-being, and promotes self-care.

# What two things do these people have in common?



# Dementia Caregiving Crisis

<https://youtu.be/a2j99vfkdgg?si=I-1ELrxHTXQ331gM>

# Who are Hawaii's Caregivers for People Living with Dementia?

Quiz

# Clinician Caregiver Engagement Questions:

- To provide the very best patient care, I find I need to also pay attention to my patients' caregivers. Can you tell me a bit about how you are feeling/doing?
- We know caregivers often neglect their own health. Do you have a primary care physician and when was the last time you saw your doctor?
- I know that many family caregivers find their role to be stressful. How are you coping with these responsibilities? How often do you get out and what do you do for fun?
- Many caregivers don't want to burden others-especially their children. Are there times when you really need help, but don't ask for fear of being a burden?
- Who helps you with support or a break with caregiving?
- Caregiving is a very hard job. We work with a social worker who has expertise in assisting family caregivers. May I help you with a referral?
- If anything should happen to you, have you made arrangements for someone to take care of (patient name here)?

# Understanding Caregiver Burden

Research has differentiated between two main types of Caregiver burden:

**Objective Burden** - refers to the physical, psychological, social, and financial impact on the caregiver caused by caregiver-related disruptions to his or her life.

- Disruptions may include the increased amount of time the caregiver takes from his or her own life to care for the care recipient.
- It may be the amount of money spent giving care. The lack of time and lack of money, produces objective burden on a caregiver.

**Subjective Burden** - refers to the physical, psychological, social, and financial impact on the caregiver caused by feelings and/or self assessment of the caregiving role.

- Some caregivers may perceive the objective tasks of caregiving as being rewarding; others may perceive them to be quite stressful and negative.
- Culture may be another factor that influences subjective burden.
- Subjective stressors, such as negative feelings toward their caregiver role or feelings of guilt about not meeting the needs of their care receiver, produces subjective burden on the caregiver.

# What are the Caregiver Burden Risk Factors?

## I. Caregiver Characteristics:

- Female gender, low education
- Live with care recipient, higher number of hours caregiving.
- Social isolation, financial stress, lack of choice.
- Coping strategies and Self-efficacy
- Culture (e.g. Asian)

## II. Patient characteristics:

- Physical stress (ADLs/IADLs); surprisingly not cognitive abilities.
- Personality, Behavior and medication management.
- Family conflict cause or effect?



# Other Risk Factors: Depression and Anxiety

A. Prevalence of depression 30-83%:

Influenced by subjective and objective stressors

Culture and ethnicity influences

Influenced by family functioning

Activity restriction (social and recreational)

Insomnia

B. Suicidal ideation: 32% in caregivers (compared to 2.7%).

C. Prevalence of anxiety 21-46% in caregivers.

# Common Chronic Diseases for Dementia vs. Non-Dementia Caregivers

Percentage of Dementia Caregivers Who Report Having a Chronic Health Condition Compared with Caregivers of People without Dementia or Non-Caregivers

Condition	Dementia Caregivers	Non-Dementia Caregivers	Non-Caregivers
Stroke	5.2	3.4	3.2
Coronary heart disease	8.3	7.2	6.6
Cardiovascular disease*	11.8	9.5	8.6
Diabetes	12.8	11.1	11.3
Cancer	14.3	13.3	11.5
Obesity	32.7	34.6	29.5

\*Combination of coronary heart disease and stroke.

Table includes caregivers age 18 and older.

Created from data from the Behavioral Risk Factor Surveillance System survey.<sup>409</sup>

# A Screening Tool for Caregiver Burden

- The Zarit Caregiver Burden scale originally designed and tested in 1980 contained 29 items, but was reduced to 22 questions.
- Adaptation of the scale made it particularly attractive. The research reported in *The Gerontologist* (2001, Vol 41, No. 5, 652-657) that a short 12-item version and 4-item screening version were found to correlate well with the full 22-item version.
- The short and simple 4-item screen, proven to be valid and reliable for its designated use, is self-administered by the caregiver.
- A score of 8 indicates high burden, and intervention may be indicated. The screen has proven to be a helpful resource tool for caregivers and their families.

# Zarit Caregiver Burden Scale

## Zarit Caregiver Burden Assessment (Screen, 4-items)

Name: \_\_\_\_\_

Date: \_\_\_\_\_

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel that because of your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)?	0	1	2	3	4
3) Do you feel strained when you are around your relative?	0	1	2	3	4
4) Do you feel uncertain about what to do about your relative?	0	1	2	3	4

### Zarit Burden Interview: Screen (4-item)

Total score range: 0 to 16

≥ 8: high burden

# Best Practices/Approaches for Caregiver Support

- Veterans Caregiver Support Program (CSP)
- Catholic Charities REACH Community
- SAVVY Caregivers Program
- Teepa Snow's Positive Approach to Care (PAC)
- Caregiver Support Groups – Alzheimer's Association, Project Dana, The Caregiver Foundation.
- Individual Counseling and/or therapy

# VA Caregiver Support Program (CSP)

- The Program of General Caregiver Support Services (PGCSS) is one of two programs under CSP.
- PGCSS offers many services, including skills training, coaching, telephone support, and online programs to caregivers of Veterans of all eras enrolled in VA.
- 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.
- 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.

# What to Know About PGCSS Enrollment:

- A Veteran receiving caregiver support services must be eligible for VA healthcare and consent to receive care from the identified caregiver.
- The enrolled caregiver will be identified in the Veteran's healthcare record.
- VA will establish a healthcare record specifically for you as a caregiver.
- To establish a healthcare record, a local VA facility Caregiver Support Program (CSP) team member will request specific information to open this record, including your full name, gender, address, Social Security Number, and date of birth.
- The facility CSP team and VA clinicians will use this healthcare record to provide you with services and support.
- Veterans providing care for a non-Veteran are also eligible to enroll with this program.
- There is a variety of caregiver psychoeducation, training and counseling services available to the caregiver in the Program of General Caregiver Support Services (PGCSS)

# VA General Caregiver Resources:

- VA S.A.V.E. Training: Caregivers play an essential role in Veteran suicide prevention. VA SAVE, which stands for Signs, Ask, Validate, Encourage and Expedite, is designed to equip anyone who interacts with Veterans to demonstrate care, support, and compassion when talking with a Veteran who could be at risk for suicide.
- Building Better Caregivers (BBC): Is an online, six-week workshop that helps caregivers in two key ways: Trains caregivers in how to provide better care to Veterans. Assists caregivers to learn how to manage their own emotions, stress, and physical health.
- Annie Caregiver Text Support: Annie, the VA's text messaging service, has several text programs for caregivers. The app. sends caregivers messages to help them manage stress, take better care of themselves, manage dementia-related behaviors, and cope with bereavement. Caregivers must have a mobile phone with the text-message capability to enroll.
- Resources for Enhancing All Caregivers Health (REACH) VA - Connect with a coach who will provide you with a workbook and help you with a variety of issues caregivers face. They will coach you in stress management, problem solving, self-care and healthy behaviors, as well as Veteran safety, behaviors, problems or concerns linked to a diagnosis. Your assigned coach will call you for a total of four sessions, over a two to three-month period. If you participate in support groups, you and other caregivers will meet together with a coach.



# Program of Comprehensive Assistance for Family Caregivers(PFCAFC)

**A. Eligibility requirements for the family caregiver** - You must be at least 18 years old. And at least one of these must be true for you:

- You're a spouse, son, daughter, parent, stepfamily member, or extended family member of the Veteran, **or**
- You live full time with the Veteran, or you're willing to live full time with the Veteran if we designate you as a family caregiver.

**B. Eligibility requirements for the Veteran** - All of these must be true for the Veteran you're caring for:

- The Veteran has a VA disability rating (individual or combined) of **70% or higher, and**
- The Veteran was discharged from the U.S. military or has a date of medical discharge, **and**
- The Veteran needs at least 6 months of continuous, in-person personal care services.

# PFC AFC Benefits

The Veteran can designate a Primary Family Caregiver, and up to two Secondary Family Caregivers as back up for the primary caregiver.

## **Eligible Primary and Secondary Family Caregivers can receive:**

- Caregiver education and training.
- Mental health counseling.
- Travel, lodging, and financial assistance when traveling with the Veteran to receive care.

## **Eligible Primary Family Caregivers may also receive:**

- A monthly stipend (payment). Amount varies based on Veteran's level of care needs and geographic residence.
- Access to health care benefits through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA)—if you don't already qualify for care or services under another health care plan.

**VA Caregiver Support Line: 1(855) 260-3274    Website: [www.caregiver.support.va](http://www.caregiver.support.va).**

# REACH Community

**REACH Community** (Resources Enhancing Alzheimer's Caregiver Health in the community), is the product of 20 years of research and clinical translations. It is a proven dementia caregiving behavioral intervention focused on information, safety, caregiver health, caregiver emotional well-being, and patient behavior management.

**REACH Community** is based on the successful **REACH VA Program** which was a clinical translation of the [Resources for Enhancing Alzheimer's Caregiver Health \(REACH II\) study](#).

**REACH** has been shown to decrease burden, depressive symptoms, the impact of depressive symptoms on daily life, the potential for abuse as measured by caregiving frustrations, and the number of troubling dementia related behaviors reported.

**REACH Community** is a caregiver support intervention delivered by certified Program Coaches. Sessions are targeted, by a risk assessment of each caregiver, and structured through protocols and scripts.

# REACH Community Catholic Charities Hawai'i

- The 4 one hour sessions are free and personalized to the caregiver's needs.
- Sessions are provided by Certified REACH Community Coaches.
- REACH Community can be offered in person or remotely.
- Caregiver self referrals are welcomed by calling Catholic Charities Hawai'i Senior Intake Line: (808)527-4777 or via email at [info@catholiccharitieshawaii.org](mailto:info@catholiccharitieshawaii.org).
- No agency referrals are accepted at this time.

# The Savvy Caregiver Program

- A 12-hour evidenced based dementia family caregiver training program. It is delivered in 2-hour sessions over a 6-week period.
- Curriculum materials include a detailed trainer's manual, a caregiver's manual, course videos, trainer's PowerPoint, and participant handouts.
- Savvy content focuses on knowledge of dementia diseases, elements of cognition, the role of confusion in dementia, caregiver self-care, identifying the person's current stage of disease, strategies for providing appropriate structure and support of daily activities, decision making, and expanding family support and community resources.
- Through weekly sessions, interactive activities, group discussions, and at-home practice, caregivers apply their new skills to meet their family's specific needs and situation.
- In multiple research evaluations since 2002, nearly all respondents reported increased skill, knowledge, and confidence, and would recommend the program to others. Caregivers also reported reduced caregiver burden, depression, and distress.

# Hawaii's Savvy Caregiver Program

- Through an ACL grant in Hawaii, 9 people were trained and 6 certified as Savvy Caregiver Trainers. Four certified Trainers are with Kula No Na Po'e Hawaii, Papakolea.
- The master trainers (Dr. Lucas Morgan and Dr. Pokii Balaz) led 6 Savvy Caregiver classes with a total of 100 family caregivers. Additionally, they provided Train-the-Trainer groups with approximately 12 facilitators who then conducted the Savvy Caregiver course for about 40 participants.
- Per caregiver feedback, and the pre/post and follow up questionnaires showed that the program improved the knowledge, skills, outlook and confidence of the participants regarding their role as a caregiver for a person living with dementia.

# Modified Versions of Savvy Caregiver:

Savvy Caregiver<sup>®</sup> Express (3 sessions), Savvy Caregiver<sup>®</sup> Advanced (follow-up program to the 6 session program focused on advanced dementia and end-of-life issues), Savvy Caregiver<sup>®</sup> Tele-Savvy (for expanded, virtual delivery), Savvy Caregiver<sup>®</sup> Express in Spanish and Mandarin, **Savvy Caregivers for Native Hawaiians.**



## **'Auamo Ke Kuleana O Nā Ma'i Poina ('Auamo Kuleana)**

Carrying responsibilities associated with dementia

**'Auamo Kuleana is a Native Hawaiian adaptation of the Savvy Caregiver Program which is an evidenced-based multi-week group program that:**

- Aims to equip caregivers with the knowledge, skills, and sense of confidence and competence needed for effective dementia caregiving.
- Focuses on guiding a person living with a dementia illness through days that are as safe, calm, and pleasant as possible.
- Provides strategies for self-care, decision-making, and seeking help from others.

'Auamo Kuleana will be facilitated weekly by KULA staff at the

**Papakōlea Community Center (lower level)**  
**Friday, July 14 - Friday, August 25 (7 weeks)**  
**9:00am - 11:00am**

For more info and to register please call **(808) 371-4015**



# Teepa Snow's: Positive Approach to Care (PAC)

- Teepa Snow is an Occupational Therapist. Her extensive professional background and personal experiences related to dementia, led to the development of a care philosophy called Positive Approach® to Care, or PAC.
- The Positive Approach to Care aims to educate the community and to help care partners understand brain changes resulting from dementia. Care partners also learn practical approaches that accommodate for those changes.
- Unlike the Global Deterioration/Reisberg scales, Teepa created a Gems state classification model that focuses on the abilities a person still has and not what they have lost. Understanding these Gem states allows care partners to provide the right care and support to help the person living with dementia shine.
- PAC is founded on the fact that instead of working with what is commonly called memory loss, they accept that people living with dementia are experiencing brain failure, it is progressive, irreversible, and a terminal disease.
- Hawaii has PAC certified independent trainers, one certified Mentor and Champion teacher, certified consultants, coaches and an engagement leader.



# Positive Approach to Care Research:

- [Research & Policy section on the PAC website](#)
- Overview of PAC interventions specifically (as of August 2022), as well as the research on which PAC interventions are based: <https://teepasnow1.b-cdn.net/wp-content/uploads/sites/9/2022/09/Overview-of-Research-Evidence-for-PAC-vs-Aug-2022.pdf>
- Here is a list of peer-reviewed citations that are a direct examination of the PAC program, or of individual interventions that make up the PAC program here: <https://teepasnow.com/resources/research-and-policy/research/>
- Family caregiver data has been solely anecdotal self-reports from surveys and post-program participation. While the reviews are overwhelmingly positive, there have been no qualitative studies to assess the impact on family caregivers health and well-being. This could be accomplished using the Caregiver Burden Indices with PAC's [Care Partner Support Series](#).
- PAC website: Teepasnow.com for information about mission, values and practical dementia care education training workshops.

# Benjamin Rose Institute on Aging and the Family Caregiver Alliance: Best Practice Caregiving

- The Best Practice database provides detailed information about the focus for each program (e.g. reducing stress, understanding dementia, planning care, skill building, health and wellness).
- The cost of program implementation, when applicable.
- Program developer information and direct utilization experiences of delivery sites and research findings.

# Other Thoughts about Caregiver Support ...

- No two caregivers are alike. A one-intervention-fits-all approach does not guarantee a decrease in caregiver burden.
- Initial caregiver needs assessment should include their safety and that of their care receivers as well as an assessment of the care receivers' physical health, depression, and anxiety.
- Interventions that place an emphasis on the individual needs of the caregivers may have the most effect in ultimately reducing their objective and subjective burden.
- Based on research, interventions that include more than one component have more positive results. For example, targeting the behaviors of the care receiver as well as providing education and support for the caregiver, have more positive results.
- Additionally, findings on the effectiveness of all types of caregiver interventions to reduce caregiver burden have been mixed. Some researchers speculate that this variability in the interventions' effectiveness stems from the fact that caregivers' situations, needs, and perceptions of stress vary significantly themselves.

# Next Steps for Caregiver Support with Dementia Care

- Need continued collaboration with government, non-profit and private agencies to address direct care workforces to meet the dementia care needs in our State.
- Establish a clearinghouse for Caregiver Support services.
- Collect data to show who may need caregiver support services but doesn't meet current eligibility requirements (e.g. Caregivers who are not employed, retired, or quit jobs to provide caregiving).
- Translate and adapt other evidence-based approaches (not developed specifically for caregiving) for use by family caregivers.
- Develop a family caregiver study program that uses an interdisciplinary track of courses from multiple academic disciplines.
- Determine where and how cultural expectations and caregiving competencies intersect and interact.
- Identify which care events trigger an assessment update and/or contingency plans.
- Begin studies about special caregiving populations and groups that have not yet been the subject of research (e.g. ID/DD, frail elderly homeless, SMI, LGBTQ, etc.).



# Caregiver Support Groups on Oahu

- Project Dana                      website: [www.projectdana.org](http://www.projectdana.org)    Ph: 808-945-3736
- Alzheimer's Association        website: [www.alz.org/Hawaii](http://www.alz.org/Hawaii).      Ph: 808-591-2771
- The Caregiver Foundation      website: [www.caregiverfoundation.org](http://www.caregiverfoundation.org)    Ph: 808-625-3782
- Hale Hauoli Hawaii              website: [www.halehauolihawaii.org](http://www.halehauolihawaii.org).    Ph: 808-292-4665
- Kokua Kalihi Valley              website: [www.kkv.net](http://www.kkv.net).      Ph: 808-848-0977
- VA Caregiver Support  
Program                              website: [www.caregiver.va.gov](http://www.caregiver.va.gov)    Ph: 1(855)-260-3274

## Mahalo and Questions?

