

*California's Caregiver Resource Centers:
Supporting Family Caregivers through
Innovation and Consumer-Directed Services*

Claudia Ellano-Ota, LCSW, Director
Caregiver Resource Center-Orange
County

A program of St. Jude Medical Center
Fullerton, CA

Hospital Association of Southern California
*Conference on Aging: A Healthy Community:
Perspectives on Aging Well*

October 15, 2013

Garden Grove, CA

OBJECTIVES

- √ Provide insight to the caregiving dynamic
- √ Introduce key components of service delivery to family caregivers
- √ Introduce services available in the community
- √ Identify innovations and partnerships with hospitals for supporting family caregivers
- √ Share new models for reaching diverse populations and adapting current service models

Family caregivers matter...

- to their loved ones and to each other.
- by making sure that medications are taken and doctor appointments are kept.
- in reducing healthcare costs and avoiding hospital readmissions.



California's Family Caregivers

- Over 6 million CA adults provided informal care for a dependent adult during 2010
- In 2009, CA caregivers provided 3.9 billion hours of unpaid care valued at \$47 billion. (AARP Public Policy Institute, *Valuing the Invaluable: 2011 Update – The Growing Contributions and Costs of Family Caregiving*. 2011)
- CA family caregivers average 21 hours of care/week
 - 1/3 live with care recipient and spend 36 hours/week (CA Health Interview Survey, 2009).

Effects of Caregiving on Caregivers' Health

- Family caregivers self-report higher levels of psychological distress and engagement in poor health-related behaviors compared to non-caregivers.
- Obesity rates, binge drinking (4+ drinks/day), and smoking rates (208% greater for those with serious distress) are higher among caregivers (CA Health Interview Survey, 2009)
- Middle-age caregivers at greatest risk for diabetes, heart disease, HBP

- (Hoffman, G.J., Lee, J., and Mendez-Luck. *Health Behaviors among Baby Boomer Informal Caregivers*. The Gerontologist, Vol. 52-2, 219-230. 2012.)

Effects of Caregiving on Caregivers' Health

- After adjusting for socio-demographic factors and physical health status, one study found that caregivers who experience strain had mortality risks 63% higher than those whose spouse was not disabled.

(Schulz, R. and Beach, S. *Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study*. Journal of the American Medical Association December 15, 1999. Vol. 282-33.)

Family Caregivers Provide Complex Chronic Care

- Family members not only provide personal care and household chores
- AARP Public Policy Institute and United Hospital Fund survey of 1,677 family caregivers to determine what medical/nursing tasks they perform
- (Reinhard, S., Levine, C., and Samis, S. *Home Alone: Family Caregivers Providing Complex Chronic Care*. AARP Public Policy Institute. September, 2012.

Family Caregivers Provide Complex Chronic Care

- 46% performed medical/nursing tasks such as:
 - Managing multiple medications including IVs and injections, helping with assistive devices for mobility, preparing special diets, wound care, using monitors, managing incontinence, and operating specialized medical equipment
 - Managing 5-9 medications
 - Reported stress due to having to learn how to manage them on their own, time consuming, having anxieties about making a mistake, and uncooperative care recipients

Family Caregivers Provide Complex Chronic Care

- Wound Care – very challenging with fears of making a mistake
- Family caregivers of chronically ill ARE the Care Coordinators
- Family caregivers received very few home visits by health care professionals if any at all
- Most who provided the most help (5+medical/nursing tasks) believed they were helping their loved one avoid institutionalization

Family Support is Linked to Better Patient Self-Management and Outcomes

Rosland, A. *Sharing the Care: The Role of Family in Chronic Illness*. California HealthCare Foundation. August, 2009

- When family members provide support to patients, patient outcomes improve
 - Better glycemic control for diabetes
 - Better blood pressure control for hypertension
 - Fewer cardiac events for heart disease
 - Better joint function and decreased inflammation for arthritis
- Patients with higher levels of support report better self-management, self-efficacy, and decreased depression

Challenges for Health Care Providers in Including Family

- Family members are not the insured
- Family members ask questions and can be time-consuming
- Family members may have unrealistic expectations
- Family members may not be competent or able to provide care but they're there
- Family members may be in conflict and may try to involve the provider

Incentives to Involve Family Caregivers

- Family caregivers are often the fiscal care managers who are actively involved in selection of providers and insurers – as well as care managers of health issues
- Supported and educated caregivers can enhance compliance and predictability
- Help ensure that Advanced Directives and POLST documents are completed
- Family may be best resource to reduce re-admissions
- Community resources can help manage family conflict about care mgmt and provide wrap-around support

Recommendations from the *Home Alone Study*

- Health care professionals must fundamentally reassess and restructure the way they interact with family caregivers in daily practice
- Health care organizations should lead and support professionals in their efforts to improve communication and training for family caregivers
- Policy makers should proactively consider family caregivers in new models of care and include caregiver assessment in Medicare/Medicaid demonstrations

California's Caregiver Resource Centers

“To Increase the Quality of Life of Caregivers by Helping Families and Communities Master the Challenges of Caregiving”



California's Caregiver Resource Centers

- 11 non-profit agencies
- Established in 1984 with landmark California legislation (AB 2913)
- Funded principally by the California Department of Health Care Services(DHCS)
- Most sites have grants from their counties to provide National Family Caregiver Support Program (FCSP) services

CRC OBJECTIVES

- Complete evaluation of the primary family caregiver and the caregiving dynamic
- Provide education and strategies to help families cope with the challenges of caregiving
- Provide opportunities to implement strategies
- Provide information about and access to community resources
- Enhance family support, knowledge, confidence, and competence in caregiving

Partnering with the CRCs

- Support and education for family caregivers in the home
 - Hospital staff do not have opportunity to see what happens after patient returns home (immediate and long term)
 - Is the needed DME there, is Home Health/home care in place, what tasks does the family have to provide? Is the caregiver capable of providing the care and tasks long-term?
 - Are there fall risks or home safety and care concerns?

Partnering with the CRCs

- There may be help at home or family involvement - but it doesn't always work smoothly
- Family Consultation and interventions can maximize efficiencies for family
- Supported and educated caregivers make a difference in patient outcomes
- CRCs support and train family caregivers to be their own Care Manager
- Increased confidence, knowledge, and lower stress can improve patient outcomes and prevent caregivers' health decline

Potential Outcomes

Outcomes with clear fiscal impact on society:

- Delay/prevent placement of care receiver into nursing home
- Improve health of caregiver (and care receiver/patient)
- Reduce emergency room visits and hospitalizations

Potential Outcomes

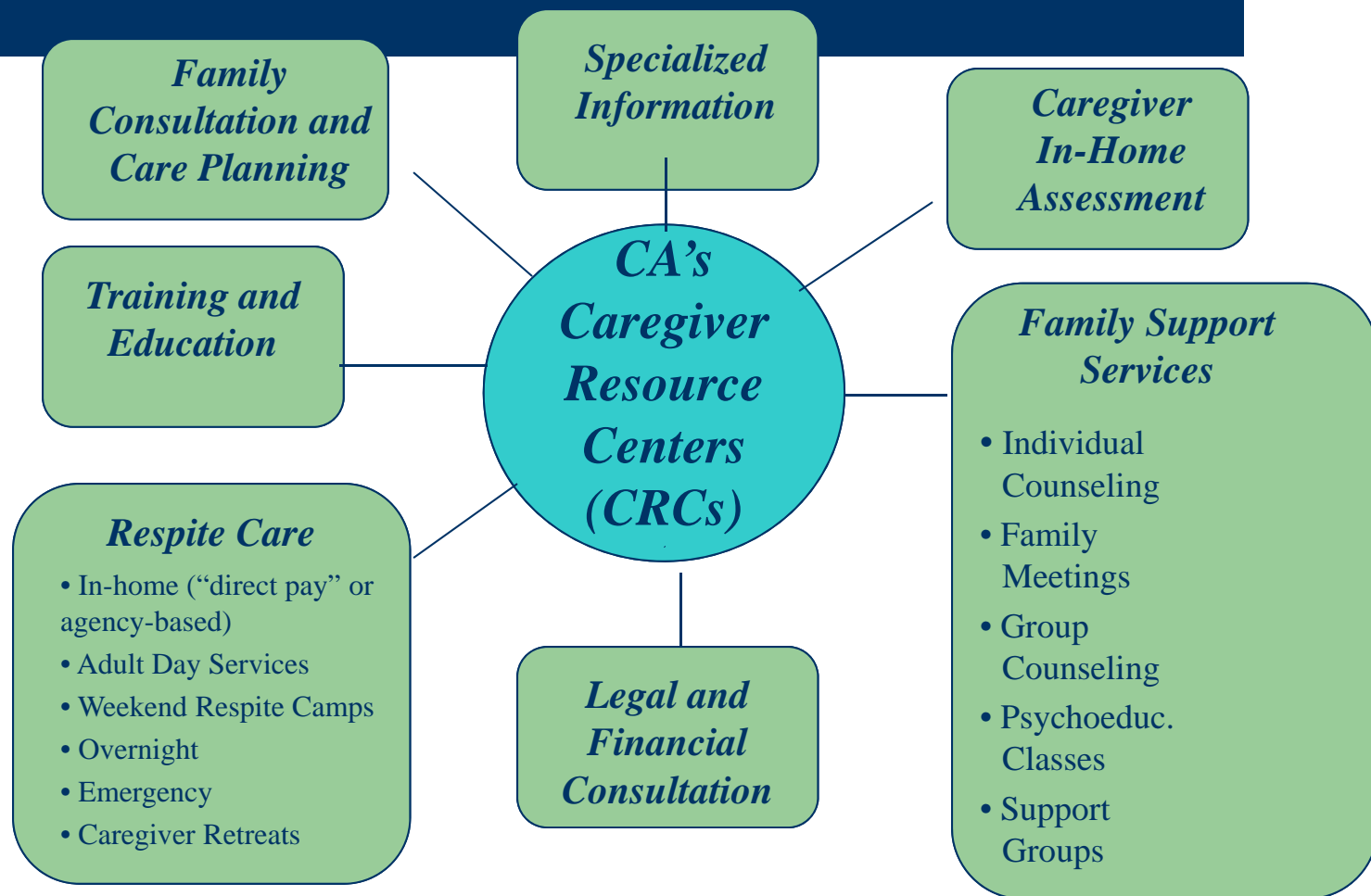
- Reduce stress
- Lower burden and/or lower “perceived burden”
- Reduce or control depression
- Increase knowledge

CRC CLIENTS

“**Family Caregivers**” = Adults caring for:

- A person(s) with adult onset cognitive (brain) impairment, traumatic brain injury or degenerative brain disease. (State funding)
- A person(s) 60 years or older unable to independently complete 2 or more activities of daily living (ADL's) (Federal OAA funding)

California's CRCs: A Range of Services and Options



ON-LINE HELP

Link 2 Care Website

Clients are provided access to a secure website with information and online support services –

www.link2care.org.



CRC/Health Care Partnerships in So Cal

- **Southern CRC (San Diego and Imperial Counties)**

REACHing OUT - prevention/early intervention mental health program for Hispanic caregivers of individuals with Alzheimer's Disease and related dementias

- REACH – **Resources for Enhancing Alzheimer's Caregiver Health**. REACH I is a group intervention and REACH II is a one-on-one intervention.

- Evidence based psycho-educational intervention for caregivers of individuals with Alzheimer's Disease and related dementias. *Designed to decrease caregiver depression, decrease caregiver burden/stress, improve caregivers' ability to cope with the memory and behavioral problems of their care receiver, improve coping skills, and improve caregiver self-care.*

CRC/Health Care Partnerships in So Cal

- ***Caregiver Resource Center – Orange County*** – a program of St. Jude Medical Center for 25 years
 - Initiative to raise awareness of end of life planning and use of Advanced Directives
 - Initiative to assist in supporting families of high risk older patients
 - Family Caregiver Education Series
 - OC's sole provider of FCSP services in a collaborative model

CRC/Health Care Partnerships in So Cal

- **Coast CRC** – (Santa Barbara, Ventura, SLO Counties) – a program of Cottage Rehabilitation Hospital
 - ***Together In Brain Injury Support***
Post-discharge support for patient and family
 - A Collaborative Program of *Coast Caregiver Resource Center (CCRC), Jodi House Brain Injury Support Center and Cottage Rehabilitation Hospital*

CRC/Health Care Partnerships in So Cal

- ***Los Angeles CRC*** – a program of Partners in Care Foundation
- CRC partners with numerous LA health care organizations and Partner's grants and programs
- Partnership with host agency to identify family caregivers through Partner's programs such as:
 - CBAS ADHC assessments, Care Transitions, and In-home Safety Evaluations

CRC/Health Care Partnerships in So Cal

Inland CRC – Riverside, San Bernadino, Inyo, Mono counties

programs pending funding to be implemented:

- T-Care
- CALMA/CUIDAR
- Family Caregiver and Senior Fall Prevention Program
- Family Caregiver Bereavement Support Program

CONTACT YOUR LOCAL CRC

- **Southern CRC**
 - 858-268-4432 <http://caregivercenter.org>
- **CRC – Orange**
 - 800-543-8312 www.caregiveroc.org
- **Los Angeles CRC**
 - 800-540-4442
 - http://www.picf.org/landing_pages/121,3.html
- **Coast CRC**
 - 805-962-3600
 - <http://www.sbch.org/tabid/799/Default.aspx>



QUESTIONS & ANSWERS