

Partnering Effectively with Family Caregivers

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KEYWORDS

- Caregiver
- Caregiving
- Critical Caregiver
- Uninformed Caregiving
- Social Determinant of Health
- Secondary Patient
- National Caregiver Support



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Family Caregivers

53 million adults in the United States

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Who are Caregivers?

- Typical U.S. caregiver – 46 yo woman who works outside the home & spends > 20 hrs/wk providing unpaid care for her mother
- Majority 35-64 yo
- Most employed – 60% full or part time
- Ethnic & minority caregivers provide more care & report worse physical health than white counterparts
- Many caregivers of older adults are also elderly with 1/3 in fair-poor health
- 1:5 caregivers provide 40 hrs of care/week increasing to 84 hrs/wk if cognitive impairment
- Average 4.3 yrs providing care – older caregivers >10 yr
- Most live with or nearby with 15% living 1-2 hours or more away

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Factors Impacting Caregiver Roles

- Age of the Population
 - Aging population with one or more chronic conditions wishing to remain at home
 - “Sandwich” generation of caregivers – caring for children & parents
- Type of Illness
 - Cognitive Impairment > stressful than physical impairment
- Long-distance Caregiving
- Urban vs Rural Settings
- Different Cultural Approaches to Caregiving

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- Buying groceries, cleaning house, doing laundry
- Helping with ADLs – getting dressed, showering, meals, transferring in and out of bed
- Making medical appointments, providing transportation
- Serving as the designated “on call” family member for problems



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Effects of Caregiving

Increasing complexity of care for longer periods of time

- Conflicting demands of jobs and family
- Increasing economic pressure
- Physical & emotional demands of long-term caregiving

Major health impact on caregivers

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• Impact on Physical & Emotional Health

- Stress
- Frustration, anxiety, exhaustion, anger & depression
- Increased alcohol & other substance use
- Reduced immune system response
- Poor physical health and more chronic conditions
- More likely to neglect their own care
- Higher mortality rates compared to non-caregivers

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Financial Issues – *especially women*

- Loss of income of the care recipient
- Loss of caregiver income
- Loss of employer-based medical benefits
- Shrinking savings to pay caregiving costs
- Threat to retirement incomes

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Work & Society

- Caregiver conflicts with caregiving & employment
- Lost productivity costs businesses \$17 billion annually
 - Workday interruptions
 - Absenteeism
 - Replacing employees who quite to provide care
- Eldercare, Employee-assistance, More flexible work schedules and benefits, Family Leave

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Legal Issues

- Especially important in the event a parent becomes cognitively impaired
- Who will manage the money?
 - Durable Power of Attorney
- Who will make health care decisions?
 - Durable Power of Attorney for Healthcare
- How to plan for long-term care
- Conservatorship
- Nurse Life Care Planner
 - American Assoc. of Nurse Life Care Planners <https://www.aanlcp.org/>
 - Nurse Life Care Planner Certification <https://cnlcp.org/>

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The Critical Caregiver Situation

Caregiving a Social Determinant of Health

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Caregivers & Complex Medical/Nursing Tasks

- Administering medication & injections
- Providing wound care
- Managing colostomies
- Inserting catheters
- Giving tube feedings
- Performing ostomy care

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The Risks of Uninformed Caregiving

- Accidental injury
- Medication errors
- Risk of neglect or abuse

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Caregiving as a Social Determinant of Health

- Caregivers face increased vulnerability & greater health risk
- Poorer health
- Reduced financial security
- Greater stress levels



Emergency for the few to treat
the complex & critical

CRISIS

Intervention for some to alleviate stressors

INTERVENTION

Awareness for everyone to promote wellbeing

AWARENESS

RNCM - Family Caregiver Partnership

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National call for health care providers to see family caregivers

“not just as a resource in the treatment or support of an older person, but also as both a partner in that enterprise and as someone who may need information, training, care, and support.”

– *Families Caring for an Aging America*, NASEM 2016.

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Consider the Family Caregiver as a “secondary patient”

- The family caregiver as patient
- Family caregivers able to effectively provide care ensures:
 - Patient well-being
 - Safe, High Quality of Care

RNCMs who include the family caregiver as their patient position the family towards positive patient outcomes

Connect the Family Caregiver with Support Resources

- Community Services
 - Adult day care
 - Respite programs
 - Senior transit
- Home Health Services
- Caregiver Support Groups
- Caregiver Self-care and Stress Relief
- Caregiver Apps and Online Information Centers

Coordinate Caregiver Skills Training

- Nursing assessment to identify skill gaps
- Interventions to train on tasks
- 24-hour nurse telephone support service
- Clear care protocols in case of emergency

Building caregiver knowledge, skills and confidence = positive effect on caregiver-patient relationship

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Provide Partnership & Psychosocial Support

- Family Caregivers often feel invisible to healthcare providers
- RNCMs can redefine the relationship through actions of partnership
 - Active listening
 - Empowerment
 - Respect
- Identify caregivers who need extra psychosocial support

Effective partnership builds caregiver resilience

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Address Family Caregiver Health

- Caregiver burden can lead to poor health
 - Higher risk for smoking, alcohol use, other substances
 - Fatigue, weaker immune system, high blood pressure, exacerbation of chronic disease
- Nurses can assess caregiver health and recommend interventions
 - Access to resources a big help

Without a healthy caregiver, the daily task of caregiving can become difficult

Impact of COVID-19 on Caregiver-Nurse Relationship

- Difficult for Caregivers
 - Frustrated with suspended services
 - Isolated from usual support system
 - Stressed by financial hardship
- Nurses
 - High stress
 - Clinics and hospitals overwhelmed
- Overcoming challenges – Reestablish Support
 - Focus on caregiver communication
 - Expanded telehealth care

Summary of Supports RNCMs Can Offer

- Information & Skills Training
- Assistance
- Counseling
- Respite
- Home modification
- Assistive devices
- Caregiver & family counseling
- Support groups



The Need for National Caregiver Support

CARE Act



- Supports better communication between health professions & family **CAREGIVERS** as they prepare for complex care at home
- **ADVISE** individuals of their opportunity to identify a family caregiver
- **RECORD** the caregiver’s name & contact information in the health record
- **ENABLE** family caregivers by providing as much notice as possible about discharge
 - Timing, discharge plan, discussing family caregiver role in carrying out the plan, instructing about medical/nursing tasks at home



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Examples of funding opportunities, cont. AARP Public Policy Institute & Family Caregiving **Home Alone AllianceSM**



The Home Alone Alliance seeks to:

1. Promote cultural change in how we support family caregivers.
2. Provide and disseminate instructional tools and other resources aimed at improving instruction for family caregivers who perform complex medical/nursing tasks.

Current Activities:

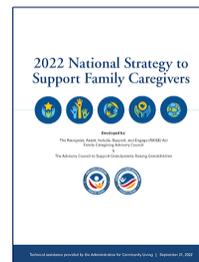
- Caregiver Instructional Video Production (i.e. Medication Management, Mobility, Wound Care)
- One-Pager Resource Guides
- In-Language (Spanish/Chinese) Material Development
- Policy – CARE Act Implementation Scan



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National Strategy to Support Caregivers

- Congressionally mandated
 - RAISE (Recognize, Assist, Include, Support & Engage) Act Family Caregiving Advisory Council
 - The Advisory Council to Support Grandparents Raising Grandchildren
- Formed in 2019 to explore & document challenges faced by family caregivers
- 2021 presented an initial report to Congress

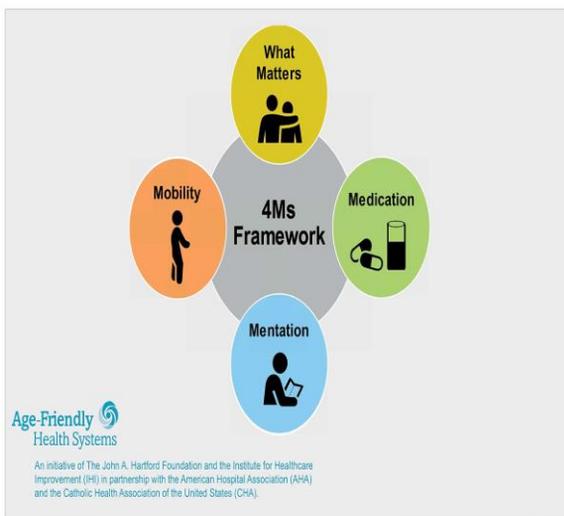


Result: National Strategy to Support Caregivers

Age Friendly Health System

Designed to meet the challenge of an aging population

- Set of Evidence-based Practices
- Cause No Harm
- Align with What Matters to the Older Adult & their Family Caregivers



Veteran Directed Care

<https://nwd.acl.gov/vdc.html>

Goal: To ease financial stress while supporting veterans living independently

- VA provides the veteran with a budget based on their care assessment
- Veterans can hire their own caregivers
- Purchase approved goods and services

Veteran Directed Provider (VDP):

- Listens to the veterans' goals
- Helps plan for services
- Connects to community resources
- Is a visible and trusted source in their community

Policy Implications

- Support for National Family Caregiver Support Program to increase education, counseling, support services
- Funding of Lifespan Respite Care
- Expansion of Family & Medical Leave Act including paid leave
- Expansion of the geriatric care workforce
- Enacting legislation to provide tax credits for family caregivers
- Strengthen Social Security by recognizing the work of family caregivers who leave the workforce to provide full time care for ill, disabled, elderly family member

