



Current & Proposed Programs

CCA The Companion Care Association (CCA) is a tax-exempt, non-profit public charity founded in 2003 in response to systemic problems encountered by caregiving families. CCA strives to help the frail elderly, people with chronic illnesses/disabilities and their caregivers lead more healthful and productive lives, while assisting care recipients of all ages to remain in their communities. Inappropriate stays in long-term care facilities would be eliminated or postponed. Our programs cut-across disease categories to empower the people they are helping, with the potential to save society much more than they cost while improving the quality of life for millions of Americans.

NEED Many of today's 50 million family caregivers are isolated and in debt. In what is being called a "caregiving crisis," caregivers often experience burnout, depression, and related problems that can lead to or aggravate chronic health conditions.¹ Nevertheless, we are increasingly reliant on them to provide essential long-term care services valued at over \$350 billion each year.

The Supreme Court's 1999 Olmstead Decision and a national initiative to "Rebalance Long-Term Care" are causing a shift away from facility-based care, leading to increased demand for home and community-based services. As America's 78 million aging baby-boomers compete for scarce long-term care services, we will need a growing number of family caregivers to fill the resource void. Yet, projections warn that we will start running out of paid and family caregivers in less than a decade. This has led to a call for "...a new paradigm for organizing and delivering long-term care in people's homes as well as in institutions."²

Our communities are slow to provide caregiving families with the accessible services they need – a problem which will intensify with the coming age wave. Companion care (or family) restrooms are a case in point. Due to a national shortage of companion care restrooms, excursions into the community can become difficult or impossible if companions are of the opposite sex and help is needed with the mechanics of toileting. The longer this problem remains unaddressed, the harder it will be to correct, as public-use construction continues with little regard for these essential facilities.

¹ Rosalynn Carter, *Addressing the Caregiving Crisis. Preventing Chronic Disease* (Atlanta: Centers for Disease Control), 2008;5(1), www.cdc.gov/pcd/issues/2008/jan/07_0162.htm. (The former First Lady is President of the Board of the Rosalynn Carter Institute for Caregiving.)

² Robert B. Friedland, *Caregivers and Long-Term Care Needs in the 21st Century: Will Public Policy Meet the Challenge? Issue Brief* (Washington, DC: 2004; Georgetown University Long Term Care Financing Project), <http://ltc.georgetown.edu/pdfs/caregiversfriedland.pdf>.

CCA is committed to advancing powerful, self-sustaining partnerships among caregiving families and their supporting communities and organizations. Working together, we can create effective new ways to meet the growing challenges they face

CCA MISSION The Companion Care Association exists to assist caregiving families enrich their quality of life by improving the caregiving process for people of all ages, including those with disabilities, the chronically ill and the frail elderly. CCA programs are designed to assist caregiving families to:

- Experience a higher quality of home and community-based care
- Feel less isolated with fewer instances of burnout and depression
- Maintain the health and productivity of employed family caregivers
- Enjoy increased amounts of respite care
- Receive more volunteer assistance in carrying out caregiver activities and in managing their households, and
- Use fewer days of hospital and nursing home care.

CCA PROGRAMS The Association's five current and proposed programs are presented below.

Telephone & Online Coaching Services for Caregiving Families – *CCA is working in cooperation with the Benjamin Rose Institute (BRI; www.benrose.org) to expand the Care Consultation program nationally. BRI's award-winning program provides caregiving families with evidence-based coaching services offered through organizations in a variety of settings.*

Guided by research-based protocols, coaches establish rapport with caregiving families, conduct a situational analysis of their needs, and empower caregivers and care-recipients to establish and carry out action plans to improve their situations. Action plans consist of a series of attainable short-term goals.³

Coaches strive to build up and maintain participant's self-confidence by empowering them to make informed decisions throughout the process. Participants receive regular telephone and online access to personal coaches in a process aimed at supporting caregiving families to limit health risks, and improve decision-making and caregiver techniques. Coaches assist caregiving families to deal with complex issues such as crisis management; family dynamics; and medical, financial and legal responsibilities. Care Consultants typically possess a bachelor's or master's degree in social work or nursing. Follow-up materials and referrals support the family's strategies for action.

³ Caregiving families will be helped to achieve their goals in different ways based on which stage of change they are in: Precontemplation, Contemplation, Preparation, Action, Maintenance or Termination. Many of today's coaches apply positive psychology and related techniques to empower participants to move from their current stage (e.g., Preparation) to the next stage (e.g., Action) on the change continuum. See Prochaska PhD, James O., Norcross PhD, John C. and DiClemente PhD, Carlo C. Changing for Good. (New York: HarperCollins Books, 1995).

CCA's *Care Consultation* activities include program development, national marketing, and customer service. CCA is also conducting market research within each targeted market sector.

Care Consultation can be offered through a variety of organizations; including health services providers, payers, voluntary health agencies, employers/unions, and affinity groups. Providers may include health plans and regional hospital systems, Continuing Care Retirement Communities, nursing homes, home health agencies, and community programs for aging in place (e.g., NORCs⁴, neighborhood villages). Payers may be health or long-term care (LTC) insurers, and possibly Medicaid programs (e.g., waived managed LTC services).

In a subsequent demonstration, we plan to expand *Care Consultation's* health promotion component and work with community service organizations to deliver coaching to the low-income caregiving families they serve. Coaching services and support materials will be available in English and Spanish.

Companion Care Restroom Accessibility – CCA is working to increase the number, quality and accessibility of companion care (or family) restrooms. We plan to expand our current efforts through an integrated national program operated with the support of voluntary health organizations and coalitions. With their collaboration, we will enlist national chains (e.g., big box stores, multiplexes, restaurants), major attractions (e.g., sports stadiums, amusement parks, museums) and public service facilities (e.g., airports, DMV's) to provide caregiving families with accessible companion care restrooms. CCA and its partners will work to have access to companion care facilities covered under Title III of the Americans with Disabilities Act. Similarly, we hope to help change restrictive state building codes that discourage construction of companion care restrooms.

To assist in locating these facilities, caregiving families and volunteers will populate a national online database and map with the locations and quality ratings of companion care restrooms. CCA will provide this information in a variety of formats. In example, a mapping service will assist travelers to locate companion care restrooms in TripTik^{®5} fashion and through GPS receivers as well as cell-phone locator systems. A Restroom Conversion Project will enlist establishments with lockable, gender-specific restrooms to designate them as companion care facilities, as well. Working with community groups, we will help ensure that new and renovated construction of commercial and public space includes a sufficient number of accessible, well-designed companion care restrooms.

Dental Health in Alzheimer's Patients – Patients with chronic illnesses and disabilities may lose their ability to self-report pain and discomfort, with some receiving inappropriate treatment caused by misdiagnosis of their symptoms. Through a demonstration program focusing on dental health and dementia, CCA proposes to help prevent or delay dental problems associated with self-reporting through innovative community networks of professionals delivering specialized preventive and restorative care to patients in the early stages of Alzheimer's disease. Caregivers will receive related training from dental hygienists. Targeted dental and palliative care for later stage Alzheimer's patients will also be addressed. Future programs will focus on other conditions and disabilities.

⁴ Naturally Occurring Retirement Communities (NORCs)

⁵ TripTik is a registered trademark of the American Automobile Association, Inc.

Community Caregiver Cooperatives – *CCA proposes to demonstrate that quality of life can improve for caregiving families when they network with volunteers in their communities. Roughly modeled after a baby-sitter cooperative, the program will assist caregiving families and their volunteer sponsors in exchanging caregiving services with other families and sponsors using a time-credit tracking system. Care Circles of volunteers will be formed around each caregiving family.⁶ Typical services provided through this mutual work credit support network will include transportation to a doctor’s appointment or respite visits to assist family caregivers in need of relief. Once provided, services are credited to the sponsored caregiving family who may then redeem them for another needed service. The Cooperative will recruit (and offer training to) participants and assist them as they schedule and track service exchanges using CCA’s online or manual systems. A website and user-friendly online database will be available to help match volunteers and caregiving families. A manual system will also be available. As the network grows, the Cooperative may provide assistance to distance caregivers and add a worksite program. This system is particularly well suited for the growing number of community programs for aging in place (e.g., neighborhood villages, NORCs⁷), offering an alternative to fee-based concierge services.*

Computer Assisted Disability Management (CADM) – Exciting computer and Internet technologies hold the promise for significant improvements in community-based long-term care (LTC) delivery. Early examples include online caregiver home-monitoring systems.⁸ *CCA proposes to help caregiving families use new and existing adaptive and web-based CADM technologies provided through innovative community LTC delivery systems.*

COOPERATING FOR PROGRAM SUCCESS CCA works in a complementary manner with other sponsoring organizations, delivering the expertise, specialized services and support needed to help proposed programs succeed. The Association conducts benchmark studies to identify best practices adaptable to our demonstration programs. Through an ongoing process of program implementation, improvement and replication, we hope to help tear down some of the more limiting barriers caregiving families encounter in their homes, communities and workplaces. Proposed demonstration programs will be revised based on participant feedback and independent program evaluation. Improved programs will be promoted nationally, with CCA and its partners assisting participating communities to access our services or develop their own adaptation of our prototypes. CCA plans to become self-sustaining through a combination of sponsorship revenues, website advertising, contributions and voluntary membership dues. User and consulting fees for software, web and technical assistance will also be considered.

CONTACT INFORMATION Contact Barry Cooper, CCA’s President, at (703) 538-6719 or by email at bcooper@companioncareassoc.org

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⁶ A Care Circle will consist of family, friends, colleagues and community volunteers who sponsor a caregiving family.

⁷ Naturally Occurring Retirement Communities (NORCs)

⁸ These systems enable caregivers to monitor and gauge the well-being of consenting home-based care recipients at a glance through secure online portals reporting motion and biometric indicators.