

Issue Paper #1
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Caregivers at Risk: A Public Health Concern

In a February 2007 *American Journal of Public Health* article, “Framing the Public Health of Caregiving,” Ronda Talley, PhD, MPH, and John E. Crews, DPA, contend that “surprisingly little attention has been focused on framing caregiving from a public health standpoint.” They argue—and we concur—that “Caregiving is an emerging public health concern that will personally affect virtually every individual. The needs of caregivers must be acknowledged by the country’s public health officials and addressed in state and local caregiver-directed programs.” We would add that in response to this public health concern, state and local policy makers must also establish caregiver support as a priority issue in legislative arenas. At the conclusion of this paper, we offer a list of policy implications and recommendations for consideration.

To support our contention that caregiving must be seen as a public health and policy issue, we incorporate information from two Fact Sheets. The first is a statistical profile of *California’s Family Caregivers* (http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1961) which cites information from several sources, including California’s Caregiver Resource Centers (CRCs). The second Fact Sheet offers a detailed look at *Caregiver Health* (http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822) and distills findings from more than 50 papers, reports and articles published between 1990 and 2006.

The Burden of Caregiving

Although family members commonly undertake care for an ill or elderly loved one willingly and find it to be a great source of personal satisfaction, caregivers themselves need support services. A large and growing body of evidence confirms that providing care for a chronically ill person can have harmful physical, mental and emotional consequences for the caregiver.

Recent medical advances, shorter hospital stays, limited discharge planning, a shortage of homecare workers, and the expansion of home care technology have

increased the caregiving responsibilities of families. Family caregivers are being asked to shoulder greater burdens for longer periods of time. In addition to more complex care, conflicting demands of jobs and family, increasing economic pressure, and the physical and emotional demands of long-term caregiving can result in major health impacts on caregivers.

National estimates show that 44 million Americans over the age of 18 provide support to older people and adults with disabilities who live in the community. *California has the highest number of family and informal caregivers of any state in the nation*, with an estimated 3.4 million Californians providing care for adult family members and friends. Caregivers in California provide 3,663,000 unpaid hours of care at an estimated value of \$36.3 billion. Most family caregivers are women, and half are employed. Most are over 50 years of age. They provide care for many years: among Caregiver Resource Center clients, the average duration is 3.8 years, with the range from less than a year to more than 60 years.

The value of this unpaid care is stunning, but it exacts a high, often hidden, cost. As you will read in the *Fact Sheet on Caregiver Health* (http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822), the impacts on the health of even initially well informal caregivers can be enormous.

Key findings:

Informal caregivers are at risk for many different physical and mental health challenges. They:

- Suffer from high levels of stress and frustration.
- Show higher levels of depression than the general population (nearly half of CRC clients show signs of depression).
- Sometimes exhibit harmful behaviors, from increased use of alcohol or other substances to higher than normal levels of hostility.
- Are in worse physical health than those not engaged in giving care. They have more chronic conditions such as heart disease, high blood pressure, diabetes and arthritis than their noncaregiving peers. They may also suffer from poorer immune function and from exhaustion.
- Neglect their own care (have lower levels of self care and preventive health behaviors than others).
- Are more likely to lack health insurance coverage due to time out of the workforce.
- Have higher mortality rates than noncaregivers of the same age.

Policy implications:

- Families, not institutions, currently provide nearly 80% of long-term care in this country. Personal health problems can take an informal caregiver out of this voluntary care workforce and lead to an escalation of costs: when a family member is unable to provide care, increased formal (paid) care is necessary, whether in the community or an institutional setting.
- Recognizing physical and psychological symptoms among family and other informal caregivers should be a public health priority.
- Improving access to appropriate mental health services and medical care is essential for at-risk spouses, sons, daughters and others who provide care to a chronically ill loved one.

Policy recommendations:

- Foster the development and delivery of caregiver assessment protocols across all care settings (i.e., for use in health care facilities, home care situations and community-based agencies) in order to develop effective support plans.
- Require assessment of caregiver as well as patient needs at the time of hospital discharge; provide appropriate caregiver training to ensure a safe transition from hospital to home.
- Encourage primary care interventions to address caregiver health.
- Advocate for continued health insurance benefits for caregivers forced to leave employment or during leaves of absence resulting from caregiving duties.
- Provide financial support to alleviate the economic stress of ongoing care.
- Provide education and support programs for caregivers.
- Increase funding for respite to reduce caregiver burden.
- Advocate for interagency coordination to provide less fragmented support for family caregivers to prolong or avoid out-of-home placement.
- Support state initiatives to assist caregivers through tax relief and increased public awareness about existing policies and programs benefiting caregivers, such as Paid Family Leave.

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Strengthening support for California's caregiving families is both cost-effective and compassionate public policy. We hope with this paper to spur the dialogue about this important health issue, and we encourage your comments on how policy makers and service and healthcare providers can address these needs. Please contact Kathleen Kelly, Executive Director, Family Caregiver Alliance, Statewide Resources Consultant, at (415) 434-3388 or kkelly@caregiver.org.

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Established in 1977, Family Caregiver Alliance (FCA) operates the Bay Area Caregiver Resource Center (CRC), one of California's 11 Caregiver Resource Centers which comprise a statewide network of nonprofit organizations authorized under state law to provide a single point of entry to support services for family caregivers throughout the state. The CRCs offer a range of services, including specialized information and publications, in-home assessment, respite, counseling and emotional support, education, and Link2Care (online support and education).

In its role as Statewide Resources Consultant, FCA also collects statewide data on caregivers and consults to the California Department of Mental Health (DMH) on program development and public education related to the California CRCs.

As a primary function of the Statewide Resources Consultant role, Family Caregiver Alliance serves as a clearinghouse of information on issues affecting caregivers. The distribution of this Issue Paper marks a new offering from FCA to share information with state policy makers and leaders to stimulate action on behalf of caregivers throughout California. Future Papers will highlight important issues affecting caregivers. If you do not wish to receive occasional Issue Papers from FCA, please let us know so that we may remove you from our distribution list. Alternatively, if you know of others who may benefit from this information, please feel free to share it.

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Family Caregiver Alliance, 180 Montgomery Street, Suite 1100, San Francisco, CA 94104, (415) 434-3388. Visit www.caregiver.org

