

CAREGIVING in Minnesota



Family, friends and neighbors often undertake caregiving willingly, and many find it a source of deep satisfaction and meaning. However, caregiving in today's economic climate amid fragmented systems of health and long-term care can take a significant toll.

Those who take on this unpaid role risk the stress, physical strain, competing demands, and financial hardship of caregiving, and thus are vulnerable themselves.

Family caregiving is an important public health concern.

CAREGIVERS SPEND

20.4 HOURS per week PROVIDING CARE

13 HOURS per month

researching services or information on disease, coordinating physician visits or managing financial matters.

On average **FAMILY & FRIENDS** PROVIDE CARE FOR **4.6** YEARS

Home ■ Shifting the care of elders away from institutional settings and back into homes and communities of choice contributes to an increasing reliance on caregivers. Without the unpaid contributions of caregivers, the health and long-term care systems would be overwhelmed by the increasing need for supportive services.

Expectations ■ Almost half of caregivers (46%) perform nursing or medical tasks. With little or no training, caregivers are providing bandaging and wound care, tube feedings, managing catheters, giving injections and intravenous fluids, and managing medications.

Access ■ Navigating the complex systems of health and long-term care is a major stressor on caregivers.

- Caregivers are managing continuity of care for their loved ones across multiple health professionals, multiple care settings, and numerous transitions.

Long-term ■ Historically, caring for ill family members was a short term endeavor, because most people did not survive to old age: They died from acute, rather than the chronic conditions of today. Caregiving is now extended – fifteen percent (15%) report caring for 10 or more years.

Taxing ■ Caregiving is a journey that often involves difficult life and death decisions, sleepless nights and an ever-present sense of grief and loss.

- Caregivers have higher levels of depression and are twice as likely to experience chronic illness as non-caregivers. More than half (55 %) of caregivers report that they feel overwhelmed by the amount of care their family member requires.

Health ■ Fifty-nine percent (59%) of caregivers report their health has gotten moderately to a lot worse because of providing care.

- Caregivers' poor health is more than just a problem for themselves. Half of family and friend caregivers who report a decline in their health, say it has also affected their ability to provide care.

CAREGIVING is all around us

Caregiving is everywhere, and thankfully so.
We humans, quite literally, can't live without it.

I have always cared
for my mother as
she has for me

I became a caregiver when my mother suffered a stroke. After hospitalization and a short nursing home stay, she was fortunate enough to return to her home. I became responsible for her health and safety, her medications, appointments, transportation, service coordination, meals, shopping, cleaning, and the other innumerable details of day to day life. I also faced the frustration of trying to decipher complex medical bills and paperwork. Caregiving was a job for which I was always on call; not just physically available, but psychologically on edge, carrying with me at all times a lingering sense of concern. This concern, of course, stemmed from the deep love I have for my mother, and it is this love that made caregiving, with all its challenges, an experience I was privileged to have.

My partner has dementia. I try to keep an eye on him all the time, because I'm afraid he'll wander off and get lost or leave a tea kettle on the stove to boil dry. I'm in my late 70s myself, and I haven't gotten a good night's sleep in months. But the worst part is how much I miss him. We used to have great conversations, but now he can't communicate with words. I'm exhausted, worried, and so sad.

The worst part
is how much
I miss him

I'm not sure I can
keep this up
much longer

I'm at the office all day in a really demanding job, but my mother needs me too. I grab a few minutes here and there to make her doctor's appointments, review rental agreements for assisted living places we're touring, field a call from my brother in Denver wanting an update on Mom, and do online research to find someone to clean her house and help her with a bath. When I finally get home, I help my daughter with her math homework and then do Mom's bill-paying. I'm dreading asking my boss for another half-day off to take her to that medical appointment. My mind is spinning, and I'm not sure I can keep this up much longer.

I became a caregiver to my father who had what I thought was a simple bladder infection that turned into me becoming a full-time caregiver for over five years now. The bladder infection became just one in a series of illnesses, which now include diabetes and Alzheimer's. I needed help to care for him but was too busy to ask for it. I'm glad there are agencies with tools and services that help folks like me get the help I need. If I had not received help, I could be facing a more serious case of chronic stress or mental illness.

One in a series
of illnesses

» **PLEASE keep Caregivers in mind**
when you are making policy decisions.



Stay tuned, this is the second
of four Caregiving in MN briefs.

» The Metropolitan Caregiver Service Collaborative is available as a resource to answer questions, connect you to research and information on caregiving, and share stories of caregivers in Minnesota.



Working together for
family caregivers

The Metropolitan Caregiver Service Collaborative (MCSC) is a voluntary organization made up of member agencies committed to

supporting family caregivers. Our vision for the future is that our community will recognize, value, and sustain the work of family caregivers.

**For more information, please contact
us at mcsc@tcaging.org**

<http://caregivercollaborative.org>



**MN Leadership
Council on Aging**

The Minnesota Leadership Council on Aging (MNLCOA) coalesces the resources and power of consumer, advocacy, social and health service organizations to advocate boldly to positive systems change for older adults and their families in Minnesota.

Seventeen leading nonprofit organizations form the Council, collectively representing or serving more than 1,000,000 seniors. Our vision is that Minnesotans will have vibrant and viable options that help them remain in their homes and communities.

www.mnlcoa.org

The sources for all of the information compiled in this brief are listed below:

Information Sources

[AARP \(2011\). Valuing the Invaluable: 2011 Update. The Growing Contributions and Costs of Family Caregiving Full Report](#)

[Gallup Healthways Wellbeing Survey, Most caregivers Look After Elderly Parent; Invest a Lot of Time. July 2011\] - Updated: November 2012](#)

[The National Alliance for Caregiving and AARP \(2009\). Caregiving in the U.S: National Alliance for Caregiving. Washington, D.C.\]](#)

[APA Stress in America™ survey 2011](#)

[Family Caregiver Alliance e- Fact Sheet: Selected Caregiver Statistics](#)

[Family Caregiver Alliance - Caregiver Health-A Population at Risk](#)

[HOME ALONE: Family Caregivers Providing Complex Chronic Care AARP Public Policy Institute, United Hospital Fund](#)