

Fact Sheet:

Informal/Family Caregivers



The Value of Family Caregiving

What do caregivers have to say about the program?

“Without the Family Caregiver Support Program I would have been sunk.”

“No one who hasn’t cared for an aged, dementia-victim loved one, could possibly know how difficult it is.”

“If it had not been for in-home respite through the FCSP I would have had to place my parents. I wish I had heard about the program years ago.”

“Great connection, I don’t feel I am the only one who has these problems”

Family Caregiver Support Program

Unpaid family caregivers, totaling more than 850,000 in Washington (WA) State are the backbone of our long-term care system. They provide 80% of the services their loved ones need to remain at home for as long as possible. Their caregiving efforts in WA are the equivalent of \$10.6 billion annually in paid care.¹ About 25% of family caregivers in our state provide at least 40 hours per week of care. Statewide data also indicates that high-intensity caregivers are five times more likely than non-caregivers to have severely poor mental health.²

Supporting unpaid family caregivers keeps Washington families together and means less people need expensive long-term care placement or services. If family caregivers become unavailable, it’s likely that adults would need to access more costly in-home and residential services.

These caregivers need support to help prolong their ongoing caregiving activities as well as ensure their own mental and physical health stays intact while coping with related challenges. Cutting edge research demonstrates that it is critical to understand how a caregiver is feeling about their role in order to better tailor the support to their individual needs.³

The Family Caregiver Support Program (FCSP), established in 2000, is available in every county in WA and offers unpaid family caregivers tailored services and resources. In fiscal year 2012, a total of \$12.5 million dollars of state and federal funds supported this program. The FCSP also leverages other funding and makes use of informal supports. A total of 8,276 caregivers received one or more of the following services:

- Information about long-term care and caregiver support services
- Assistance in gaining access to supportive services
- Evidence-based assessment of caregivers' needs and care planning
- Caregiver support groups
- Caregiver training and education (increasing skill building and self-care)
- Counseling/Consultation services to cope with challenges
- Respite care services (in and out-of home settings) to provide breaks
- Supplemental Services such as bath bars and incontinent supplies
- Health and wellness referrals to cope with depression and medical issues

Family Caregivers reported:

"I wanted to let you know how much your program has impacted my ability to care for my mother."

"Thank you so much, I feel like a huge weight has been lifted off my shoulders."

"I could not handle caregiving without you and the FCSP."

"I am thankful for the FCSP program because I didn't know where to turn for help. I enjoy coming to the support group. It's an opportunity to get out and associate with others and also getting some self-care is a good thing."

The FCSP can make a difference in the lives of caregivers if they get the right supports at the right time....before it is too late!

For More Information

www.adsa.dshs.wa.gov/caregiving
or call 1-800-422-3263.

Tailored Caregiver Assessment and Referral (TCARE®)

Beginning in July 2009, the Aging and Disability Services Administration and the state's 13 Area In Agencies on Aging began incorporating an evidence-based screening/assessment and consultative care planning intervention, called Tailored Caregiver Assessment and Referral (TCARE®), into the Family Caregiver Support Program. Developed by internationally renowned caregiving expert, Rhonda Montgomery, Ph.D (University of Wisconsin-Milwaukee), TCARE® is designed to assess the stress, depression and burdens of unpaid family caregivers and recommend strategies and services that can best help those caregivers who are most burdened with their caregiving responsibilities. With TCARE®, caregivers are:

- Offered a broader service package through an individualized care plan;
- Provided more consistent services across the state;
- Educated and empowered to seek out available community resources;
- Provided the right service at the right time.

WA State participated in a national TCARE® outcome study in 2008-2009. The results indicate that the TCARE® process effectively reduces sources of caregiving stress and improves mental health outcomes for caregivers. Caregivers who participated in TCARE® had statistically significantly about the caregiving role) than caregivers in the control group who received "regular" services lowered stress, depression, relationship burden and identity discrepancy (how they feel without TCARE®. The family caregivers who received "regular" services, without the use of TCARE®, through the Family Caregiver Support Program, actually got worse in each of these measures.

Family Caregiver Support Program Caregivers and Care Receivers

The Legislature increased state funding for the FCSP for 2012 by \$3.45 million to serve 1,500 new family caregivers.

Caregivers who received services from WA State's FCSP in 2012:

- 36% have provided care for five years or more;
- 56% are over age of 60 and most are caring for their husband or a parent;
- 31% work full or part-time;
- 54% are caring for loved ones with Alzheimer's or a related dementia;
- 50% experienced a high level of depression;
- 45% rate their health as fair, poor, or very poor;
- 52% of caregivers would consider residential placement for their loved ones if the current caregiving situation worsens.

Care Receivers whose caregivers received services from WA State's FCSP in 2012:

- 40% look to be financially eligible for Medicaid Long Term Services & Supports (LTS) at the time of caregiver's initial assessment.
- 76% look to be functionally eligible for Medicaid LTSS.

National research indicates that family caregivers are a population at risk, as their caregiving can lead to impaired health, high levels of depression, stress and burn-out, and are ultimately at higher risk of mortality. The stakes of not supporting family caregivers are too high to ignore.

1. Feinberg, L., Reinhard, S., Houser, A. & Choula, R. (2011) Valuing the Invaluable: 2011 Update: The Growing Contribution and Costs of Family Caregivers, Washington DC: AARP Public Policy Institute
2. LeMier, Mary. (2008, October) Behavioral Risk Factor Surveillance System, Caregiver Analysis, WA State Department of Health
3. Savundranayagam, M., Montgomery, R. J. V., Kosloski, K. (2010, December). *A Dimensional Analysis of Caregiver Burden Among Spouses and Adult Children*, The Gerontologist