

About National Family Caregivers Association

National Family Caregivers Association educates, supports, empowers and speaks up for the more than 65 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers’ lives by removing barriers to health and well-being. For more information, visit www.thefamilycaregiver.org.

About Allsup

Allsup is the premier provider of Social Security disability representation and Medicare plan selection services. Serving individuals with disabilities for more than 25 years, Allsup was founded as the first nationwide, non-attorney service helping people receive their SSDI benefits. In its history, Allsup has successfully secured disability benefits for more than 170,000 deserving customers to help them lead lives that are as financially secure and as healthy as possible. The company is based in Belleville, Ill., near St. Louis. For more information, visit www.allsup.com.

For a free SSDI eligibility screening, please call (888) 841-2126 or visit NFCA.Allsup.com. For information on *Allsup Medicare Advisor*® please call (866) 521-7655 or visit NFCA.Allsup.com.

Contacts:

Allsup
Tai Venuti
(800) 854-1418 ext. 68573
t.venuti@allsupinc.com

National Family Caregivers Association
Lisa Winstel
(301) 942-6430
lisa.winstel@thefamilycaregiver.org

The NFCA/ Allsup Family Caregiver Survey was an online survey of 1,579 family caregiver members of National Family Caregivers Association who subscribe to the organization’s E-letter. Surveys were completed in March and April of 2011. This is not a random sample of all caregivers. However, the findings provide important insights to the challenges and issues facing this group of higher burden family caregivers. Richard Day Research, an independent market research firm based in Evanston, Ill., was responsible for data management, analysis and reporting. A summary report is available at <http://www.allsup.com/Portals/4/NFCA-Caregiver-Survey10.11.pdf>.



Higher-Burden Family Caregivers:
An Update From
National Family Caregivers Association and Allsup



“Allsup is pleased to collaborate with NFCA to advance our understanding of America’s family caregivers. The primary concerns cited in the survey include physical and mental health, financial needs and respite care—and they are all inter-related.”

“Allsup helps people identify and make the most of the resources available to them. We recognize the importance of supporting other expert organizations, like NFCA, to provide the comprehensive programs and services individuals want and need.”

– Tai Venuti, Allsup manager of Strategic Alliances

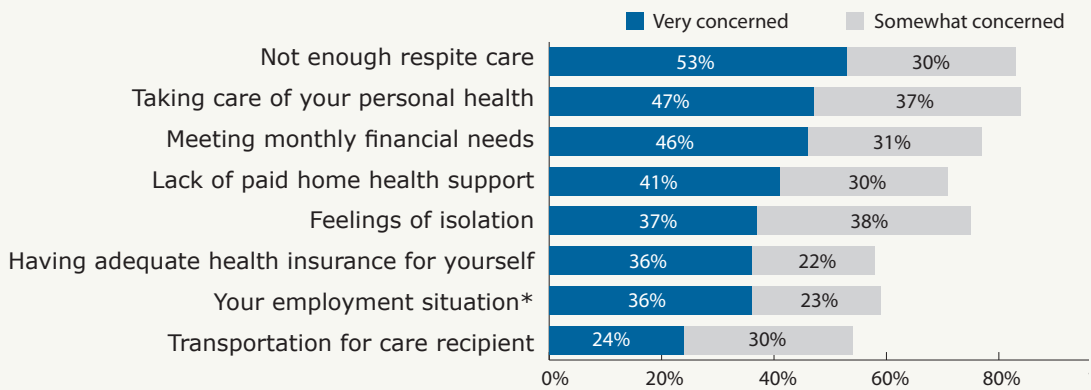
The National Family Caregivers Association (NFCA) and Allsup, a nationwide provider of Social Security Disability Insurance (SSDI) representation and Medicare plan selection services, conducted the *NFCA/Allsup Family Caregiver Survey* to gain a better understanding of the needs, concerns and wants of long-term and “higher-burden” family caregivers.

Higher-burden family caregivers devote more hours to caregiving, help with more activities of daily living (ADLs) and instrumental activities of daily living (IADLs) and have been doing so for many more years than the majority of the nation’s 65 million caregivers.

Taking care of personal health topped the list of concerns cited by more than 1,500 family caregivers responding to an April 2011 survey.

Top Concerns of Caregivers

- Lack of respite care is the top concern among caregivers, followed by taking care of their own health.
- Students and those unemployed and looking for work rank unemployment situation more prominently.



“It is gratifying to see our core message of protecting your health and maintaining your physical and emotional well-being resonates with our members. Too often caregivers are so focused on other people’s needs that they neglect their own. This feedback tells us our members recognize the importance of self-care. They have internalized our message that if they cannot take care of themselves, they cannot take care of their loved ones.”

— Suzanne Mintz, NFCA CEO

Providing More ADL Assistance

Family caregivers of loved ones with debilitating chronic conditions tend to provide the most ADL assistance. Family caregivers of children, adult children and spouses/partners also provide more ADL assistance.

Avg. # of ADLs Helping With (Overall= 2.6 of 6)	Providing More ADL Assistance
Who care for?	Child 3.2 Spouse or partner 2.7
Where recipient lives?	Caregiver home 3.0
Age of recipient	18 to 24, 3.3
Primary diagnosis	Muscular dystrophy 5.2 ALS 4.4 Cerebral palsy 4.4 Spinal disease/damage 4.0
Years as caregiver	5+ years 3.0
Caregiving role	Suddenly thrown into it 3.0
Caregiving help	Primary with help 3.1
Employment status	Full-time family caregiver 4.1

Providing More IADL Assistance

In addition to providing help with more than 4 ADLs, full-time family caregivers provide assistance with more than 6 IADLs.

Avg. # of IADLs Helping With (Overall= 4.9 of 7)	Providing More IADL Assistance
Who care for?	Spouse 5.3
Where recipient lives?	Caregiver home 5.5
Age of recipient	65 to 74 5.2
Primary diagnosis	Cerebral Palsy 5.8 Autism 5.6 Diabetes 5.5 Brain damage 5.4 MS 5.4 Parkinson’s 5.4 Spinal disease/injury 5.3
Years as caregiver	5+ years 5.3
Caregiving role	Suddenly thrown into it 5.4
Caregiving help	Primary with help 5.4, Sole caregiver 5.4
Employment status	Full-time family caregiver 6.1, Unemployed 5.7, Student 5.5

Forty-six percent of NFCA members were thrust into family caregiving suddenly and nearly 87 percent are the sole caregiver or the primary caregiver. In comparison, only 32 percent of the respondents to “Caregiving in the U.S. 2009” represented themselves as the sole caregiver.

Concerns by Caregiving Role

Sole providers are the most concerned about the challenges of caregiving, especially not enough respite care and feelings of isolation.

% “Very” Concerned about	Caregiving Roles			
	Sole provider	Primary with help	One of many who share	Help but not primary
Not enough respite care	62%	52%	24%	32%
Taking care of your personal health	53%	45%	34%	35%
Meeting monthly financial needs	53%	40%	42%	32%
Lack of paid home health support	47%	36%	32%	34%
Feelings of isolation	47%	32%	21%	18%
Having adequate health insurance for yourself	41%	31%	34%	20%
Your employment situation	41%	32%	34%	26%
Transportation for care recipient	27%	21%	22%	23%

Source: 2011 NFCA/ Allsup Family Caregiver Survey

Concerns by Evolution of Caregiving Role

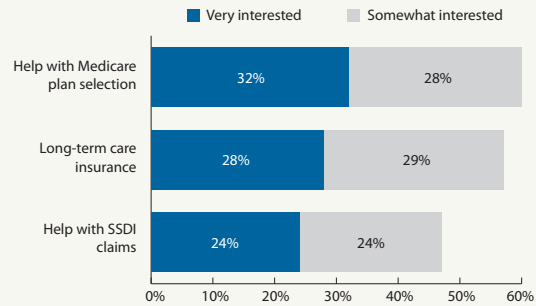
Those thrown suddenly into the caregiving role are the most concerned about the challenges of caregiving, especially not enough respite care.

% “Very” Concerned about	Evolution of Caregiving Role	
	Thrown suddenly into role	Role developed slowly over years
Not enough respite care	60%	46%
Taking care of your personal health	53%	42%
Meeting monthly financial needs	51%	42%
Lack of paid home health support	46%	36%
Your employment situation	42%	31%
Feelings of isolation	41%	34%
Having adequate health insurance for yourself	40%	32%
Transportation for care recipient	25%	22%

Source: 2011 NFCA/ Allsup Family Caregiver Survey

Interest in Services

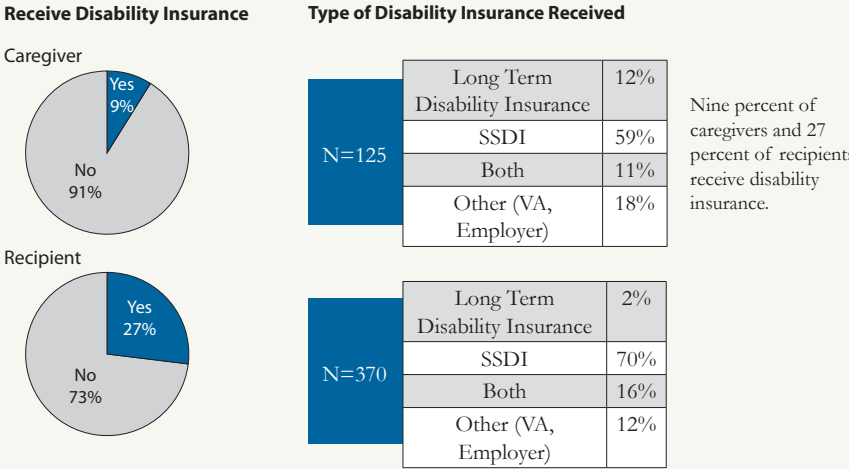
The majority of caregivers were interested in help with Medicare plan selection and long-term care insurance. Nearly one-half were interested in help with Social Security Disability Insurance (SSDI) claims.



Source: 2011 NFCA/ Allsup Family Caregiver Survey

Disability Insurance

Social Security Disability Insurance is the primary type of disability insurance caregivers and care recipients receive.



Source: 2011 NFCA/ Allsup Family Caregiver Survey

This information will help NFCA advocate for, develop and implement programs that support family caregivers, improve their quality of life and provide resources and information that will help them avoid crisis situations. The data will also contribute to the growing but still limited research literature on sub-sets of America’s caregivers.