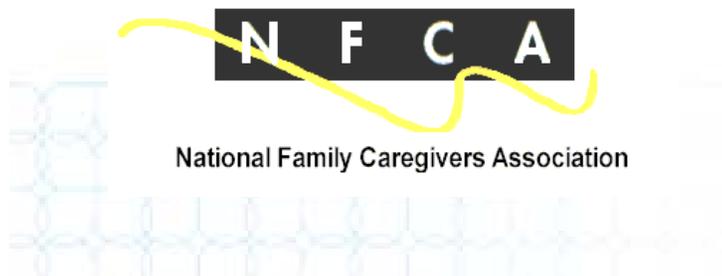


# NFCA/Allsup Family Caregiver Survey

Insight into the concerns, interests and activities of  
higher burden family caregivers

October 2011

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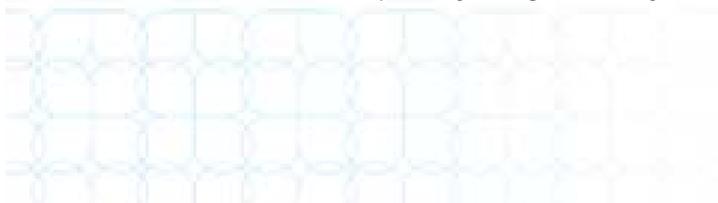
# NFCA Family Caregivers

Many family caregivers take on a significant and sustained burden of care.

The survey found that NFCA member family caregivers care for loved ones across the lifespan.

- 42 percent care for a parent.
- 36 percent care for a spouse.
- 14 percent care for a child.
- 69 percent are in their middle years, ages 45 to 64.
- 48 percent are employed full- or part-time.

Source: 2011 NFCA/Allsup Family Caregiver Survey



# Characteristics of a Higher Burden Caregiver

Survey data suggests a family caregiver is likely to experience a higher burden (e.g., assist in more personal care activities such as bathing, feeding and toileting and/or provide more instrumental care, such as arranging transportation and managing finances) if they:

- Care for a spouse or parent who is 65 or older.
- Live with their care recipient.
- Feel as if they were thrown suddenly into their caregiver role, as opposed to their role developing slowly over years.
- Have been providing care for more than five years.
- Care for a loved one whose condition severely limits their ability to care for themselves, such as, Alzheimer's or Parkinson's disease, muscular dystrophy, spinal cord or brain injury.
- Are the sole or primary caregiver.
- Are a full-time family caregiver.

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Caregiver Demographics

More than two-thirds of caregivers are 45-64 years of age, nearly one-half have household incomes less than \$40,000 and about one-third are employed full time.

Age	
18-24	<1%
25-34	3%
35-44	11%
45-54	31%
55-64	38%
65-74	13%
75+	4%

Household Income	
Under \$25,000	23%
\$25,000 to \$39,999	22%
\$40,000 to \$59,999	20%
\$60,000 to \$74,999	13%
\$75,000 to \$99,999	11%
\$100,000 or more	11%

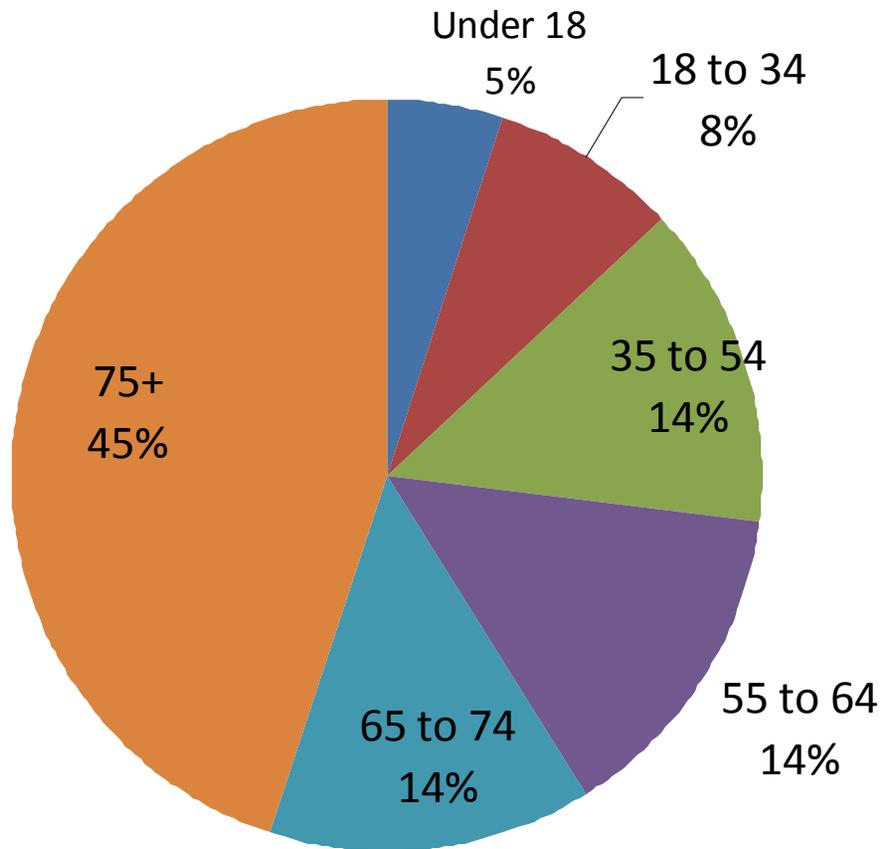
Ethnicity (of those providing)	
White	85%
African-American/ Black	8%
Hispanic	3%
Other/ Mixed / Refused	4%

Employment	
Full-time	34%
Part-time	14%
Full-time family caregiver	15%
Retired	18%
Homemaker	4%
Student	1%
Unemployed	14%

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Care Recipient Age

Care recipients 75 years of age or older are most likely cared for by one of their children, while care recipients 65 to 74 years of age are most likely cared for by a spouse or partner.

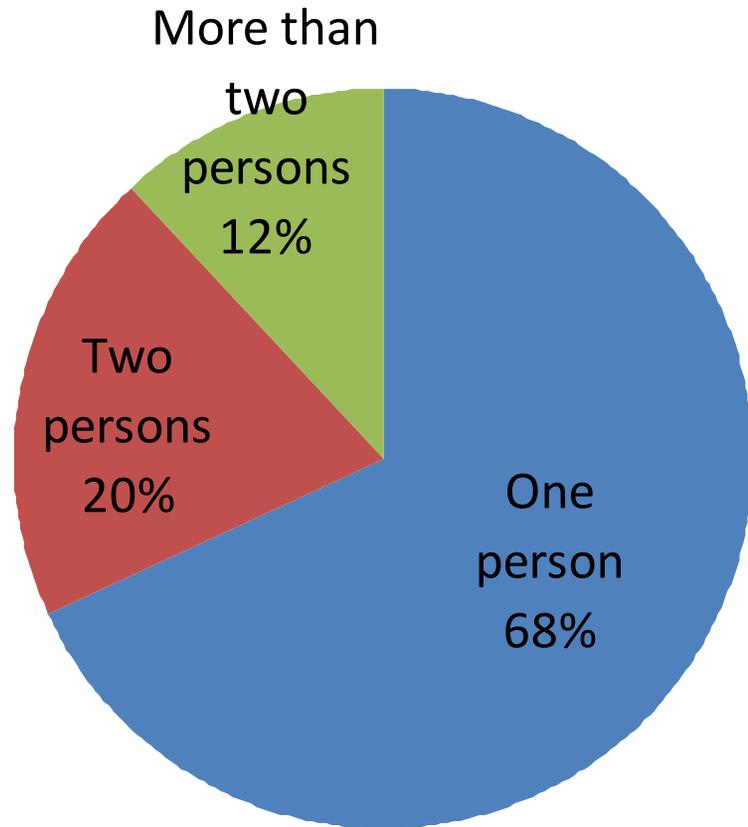


- Almost half of care recipients are 75 years of age or older.
  - Most of these are parents whose children are caring for them.
- 14 percent of care recipients are 65-74 years of age.
  - Most of these are cared for by a spouse/partner.

Q: How old is your care recipient?

Source: 2011 NFCA/Allsup Family Caregiver Survey

# How Many People Under Caregiver's Care

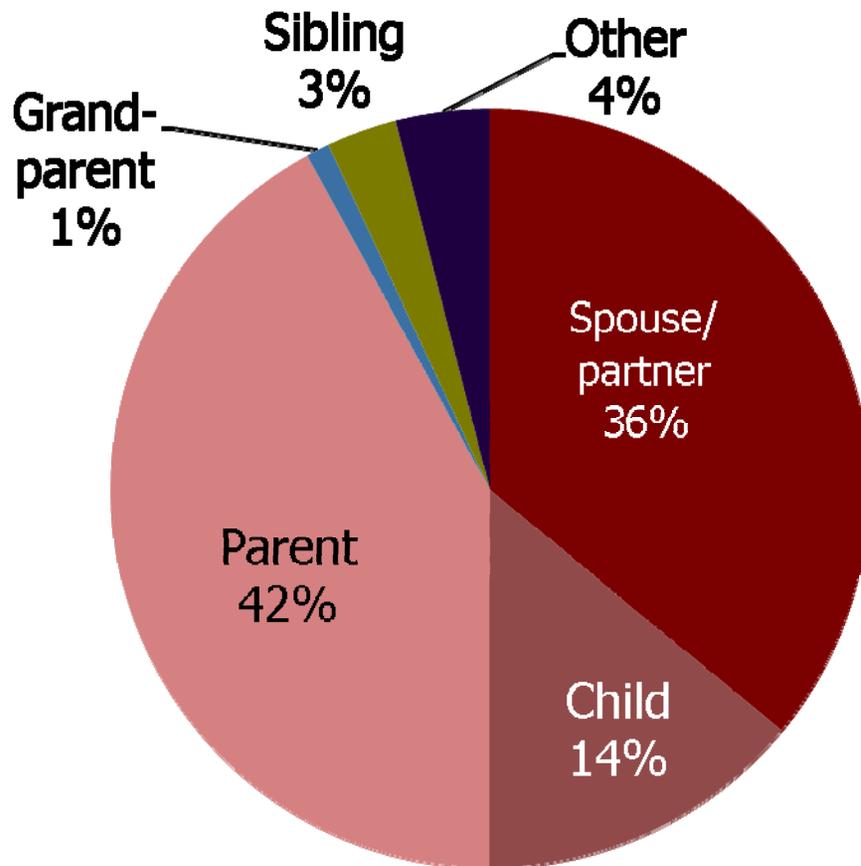


One-third of caregivers are providing care to more than one person.

Q: For how many people, including adults and children, do you provide care?

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Primary Care Recipient's Relationship

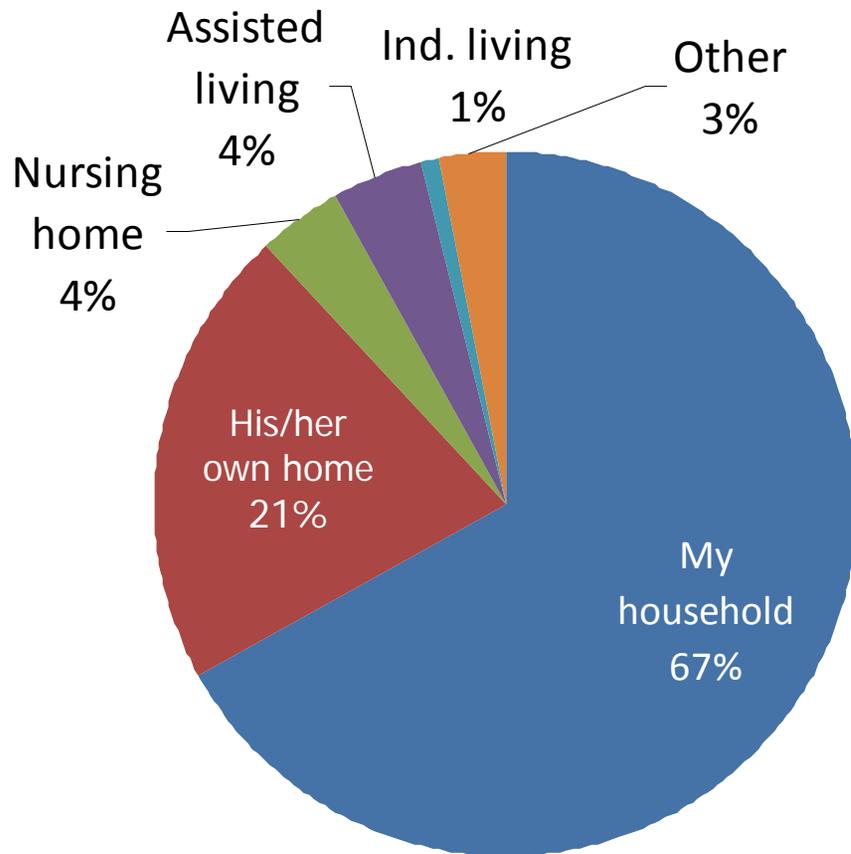


- The greatest percentage of caregivers are primarily caring for a parent.
- More than one-third are primarily caring for a spouse or partner.
- 14 percent report providing the most care to a child.
  - Within this group, 71 percent are providing care to an adult child.

Q: Please indicate your relationship to the person for whom you provide the most care.

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Where Does Care Recipient Live?



Two-thirds of caregivers report that their care recipient lives with them.

Q: Where does your care recipient currently live?

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Where Does Care Recipient Live?

The majority of care recipients live in the caregiver's household.

Where Live?	Who providing care for?			
	Spouse	Child	Parent	Other
My home	92%	88%	44%	43%
Their home	2%	6%	39%	39%
Nursing home	3%	0%	7%	4%
Assisted living	2%	1%	6%	3%
Ind. living	0%	1%	1%	10%
Other	1%	4%	3%	1%

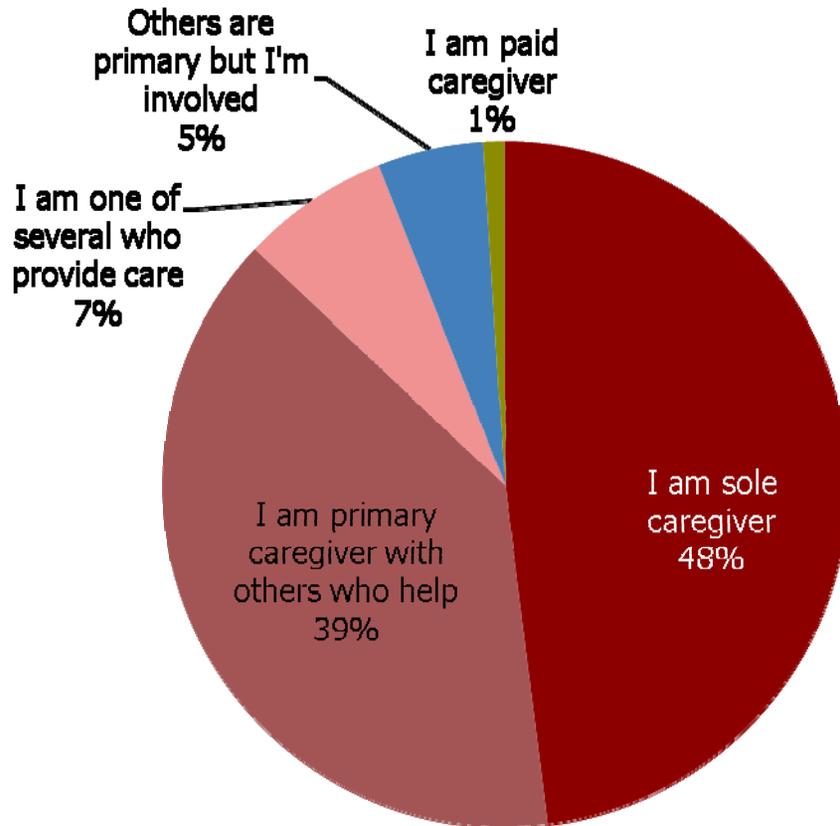
- Virtually all caring for a spouse report their care recipient lives with them.
- 44 percent of those who care for a parent are living with them (in the caregiver's home).

Q: Where does your care recipient currently live?

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Caregiver Role

Nearly two-thirds of spouses say they are the sole caregiver and report the lowest levels of additional help.



- Almost one-half of caregivers report they are the sole caregiver.
- Spouses are most likely to be sole caregivers.

Role	Who providing care for?			
	Spouse	Child	Parent	Other
Sole	65%	33%	41%	30%
Primary w/help	32%	51%	42%	32%
One of several	1%	10%	10%	19%
Help others	2%	5%	7%	13%
Paid	0%	1%	0%	6%

Q: Which of the following statements best describes your caregiving role?

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Primary Diagnosis of Care Recipient

Caregivers are faced with a wide array of conditions, but the top nine account for two-thirds of all diagnoses.

## Primary Diagnosis\* of Care Recipient (Top Responses)

(n=1,496)	%
Alzheimer's disease (confusion, dementia)	21%
Stroke and related disorders	12%
Multiple Sclerosis	8%
Brain damage or traumatic brain disease	6%
Parkinson's disease	5%
Spinal disease or disorder / spinal cord injury	5%
Cancer	4%
Heart disease	4%
Aging (volunteered)	2%
Many others <3%	

- Alzheimer's disease was mentioned most often, with one in five reporting this was the care recipient's primary diagnosis.
- Aging was not listed as a choice, but 2 percent of respondents volunteered that aging was the primary diagnosis.
- \*Note: Survey asked only for primary diagnosis and did not capture information on co-morbid conditions.

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Primary Diagnosis by Relationship

Brain damage and stroke-related diagnoses are common among three of the four groups.

- Alzheimer's is the dominant diagnosis of those caring for a parent.
- Multiple sclerosis is the dominant diagnosis of those caring for a spouse.

Caring for			
Spouse	Child	Parent	Other
Multiple sclerosis 18%	Cerebral Palsy 18%	Alzheimer's 33%	Alzheimer's 23%
Stroke-related 17%	Brain damage 16%	Stroke-related 13%	Brain damage 12%
Alzheimer's 13%	Developmental disorder 12%	Heart disease 7%	Cancer 7%
Spinal disorder 9%	Autism 7%		Mental illness 7%
Brain damage 8%	Spinal disorder 5%		Stroke-related 7%
Parkinson's 8%			Developmental disorder 6%
Cancer 5%			

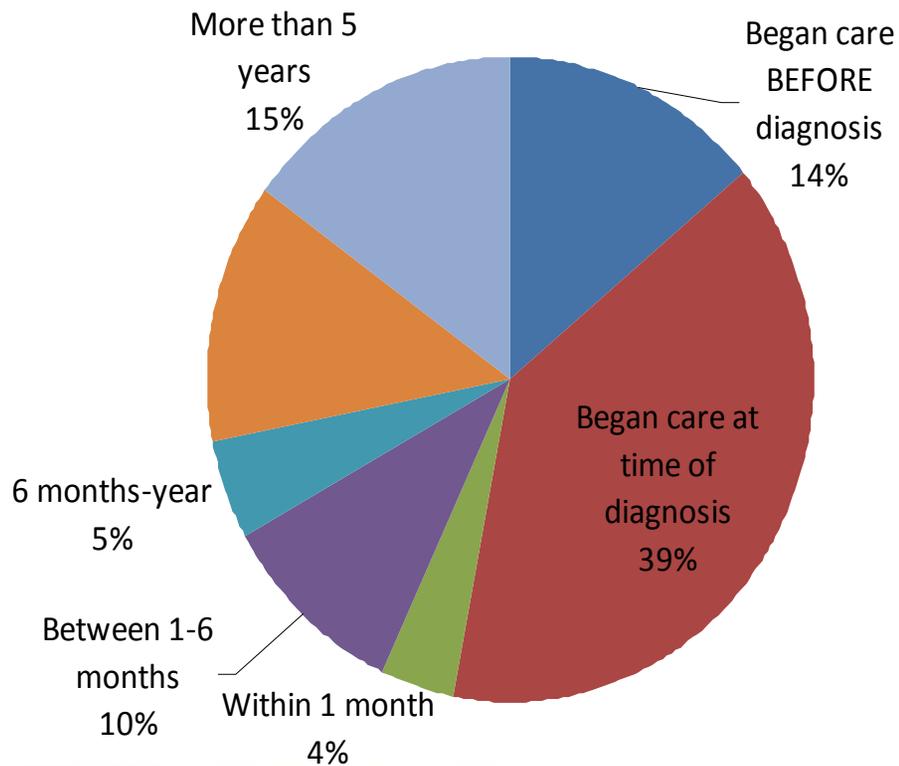
Note: Only diagnoses reported by 5%+ of each group shown.

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Which Came First-Diagnosis or Caregiving?

For a majority of caregivers, caregiving began immediately: either right at diagnosis or before a diagnosis.

## Diagnosis to Caregiving Gap

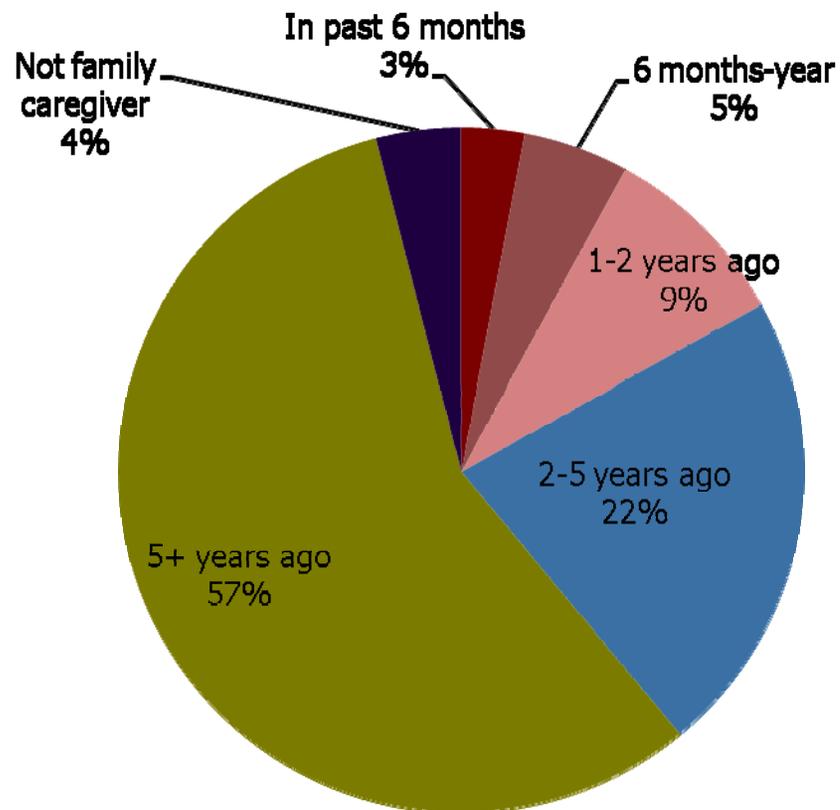


When care began	Who providing care for?			
	Spouse	Child	Parent	Other
Before diag.	10%	23%	16%	14%
At diag.	35%	54%	39%	24%
Within year	23%	15%	20%	18%
1 to 5 years	13%	4%	15%	11%
>5 yrs.	19%	4%	10%	33%

Caregiving began before or at the time of diagnosis for more than three-fourths of those caring for a child, more than one-half of those caring for a parent and almost one-half of those caring for a spouse.

Source: 2011 NFCA/Allsup Family Caregiver Survey

# When Did You Think of Yourself as Family Caregiver?



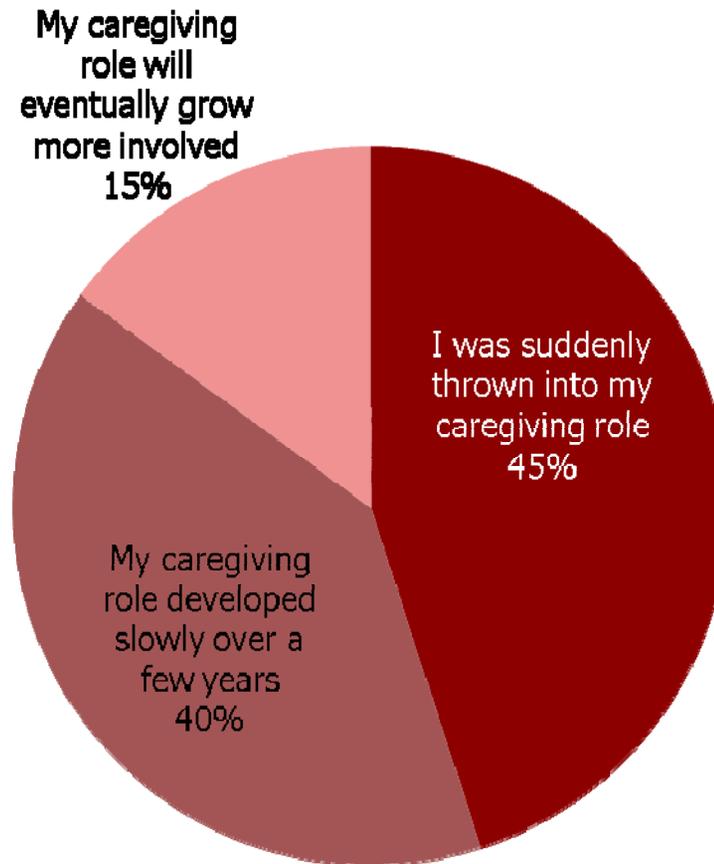
A majority of respondents have thought of themselves as a family caregiver for more than five years.

Q: When did you think of yourself as a family caregiver?

Source: 2011 NFCA/Allsup Family Caregiver Survey

# How The Caregiver's Role Evolved

Almost one-half of caregivers felt like they were suddenly thrown into the caregiver role.

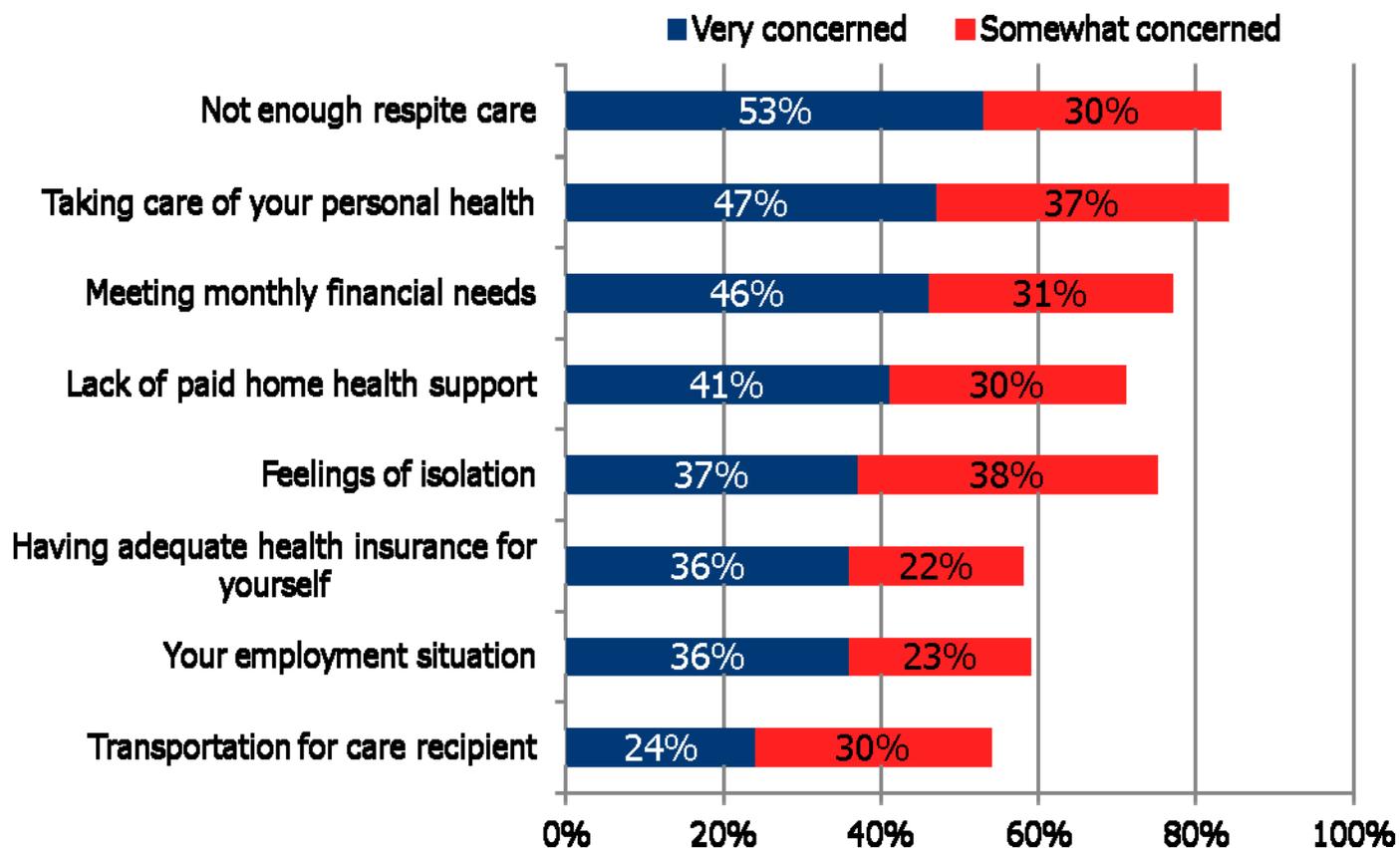


Q: Which statement best describes your situation?

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Top Concerns of Caregivers

When it comes to their own situation, caregivers are most concerned about taking care of their own personal health, not having enough respite care and meeting monthly financial needs.



Q: Please rank your level of concern about the following challenges you face as a caregiver (Very, Somewhat, Not Very, Not at All)

Source: 2011 NFCA/Allsup Family Caregiver Survey

# 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 Role			
	Sole provider	Primary with help	One of many who share	Help but not primary
Not enough respite care	<b>62%</b>	52%	24%	32%
Taking care of your personal health	<b>53%</b>	45%	34%	35%
Meeting monthly financial needs	<b>53%</b>	40%	42%	32%
Lack of paid home health support	<b>47%</b>	36%	32%	34%
Feelings of isolation	<b>47%</b>	32%	21%	18%
Having adequate health insurance for yourself	<b>41%</b>	31%	34%	20%
Your employment situation	<b>41%</b>	32%	34%	26%
Transportation for care recipient	<b>27%</b>	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.

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

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Concerns by Duration of Caregiving

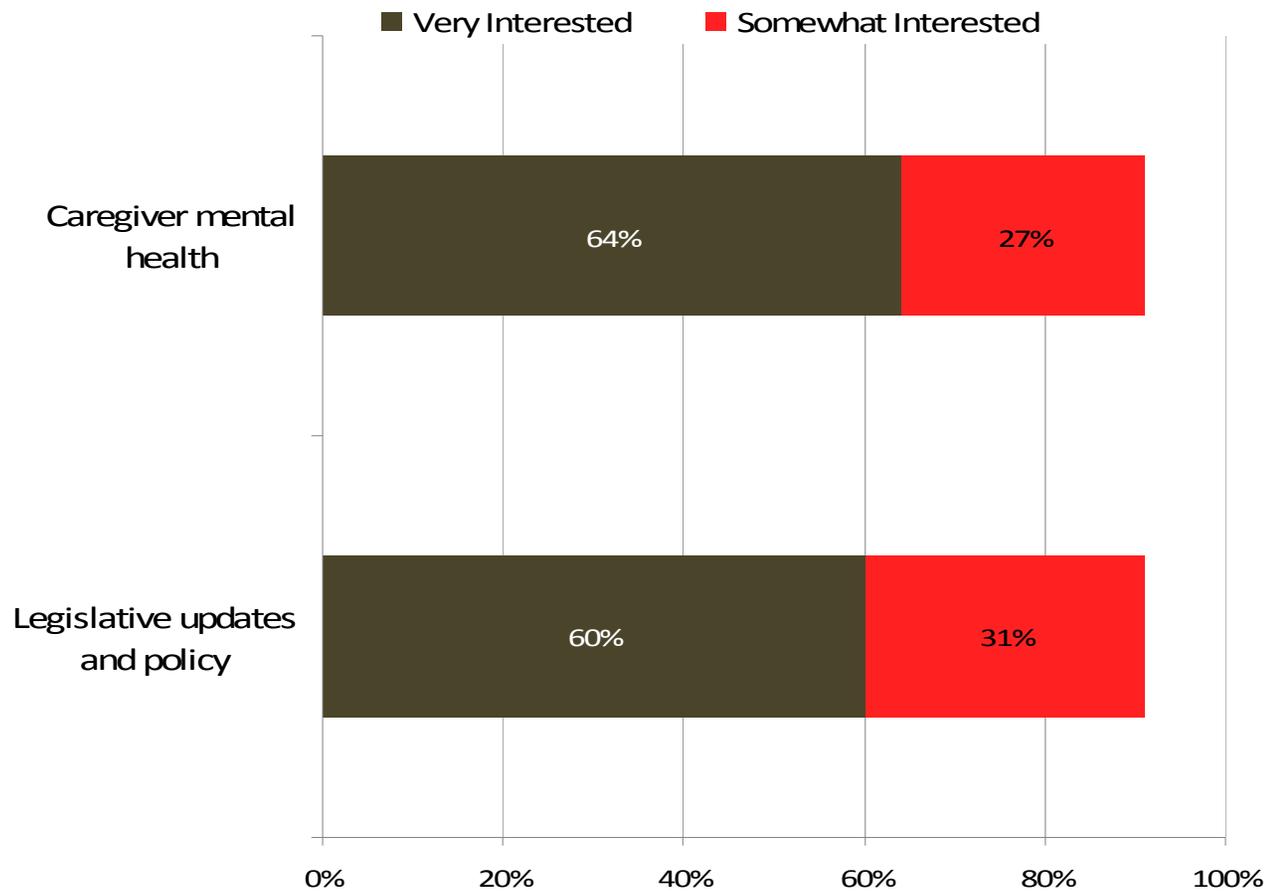
Caregiver concerns generally increase over time. Only concern about the caregiver's own employment situation decreased over time.

% "Very" Concerned about	Duration of Caregiving			
	Less than 1 year	1-5 years	5-10 years	More than 10 years
Not enough respite care	45%	53%	51%	58%
Taking care of your personal health	43%	45%	48%	51%
Meeting monthly financial needs	47%	45%	45%	48%
Lack of paid home health support	40%	39%	41%	44%
Feelings of isolation	32%	35%	38%	40%
Having adequate health insurance for yourself	37%	31%	38%	38%
Your employment situation	43%	36%	36%	35%
Transportation for care recipient	20%	23%	22%	27%

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Topics of Interest

Caregiver mental health and legislative updates and policy topped a list of caregiver interests with 91 percent very or somewhat interested in both topics.

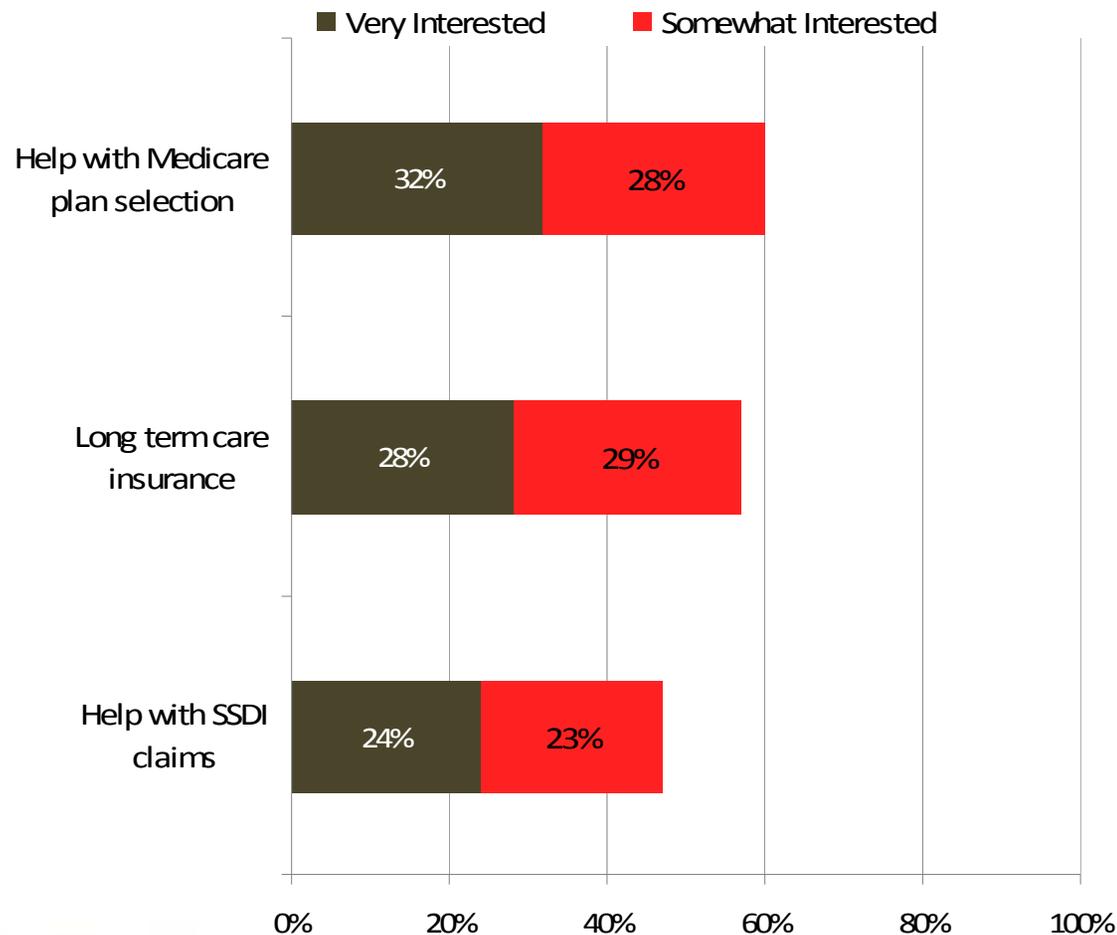


Q: Please rate your interest in the following topics as they relate to family caregiving.

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.



Q: Please rate your interest in the following services as they relate to family caregiving.

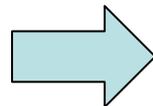
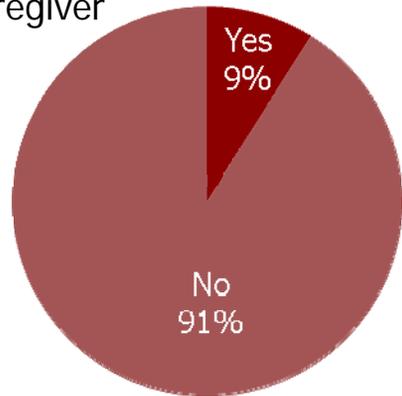
Source: 2011 NFCA/Allsup Family Caregiver Survey

# Disability Insurance

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

## Receive Disability Insurance?

Caregiver



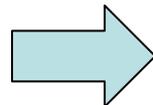
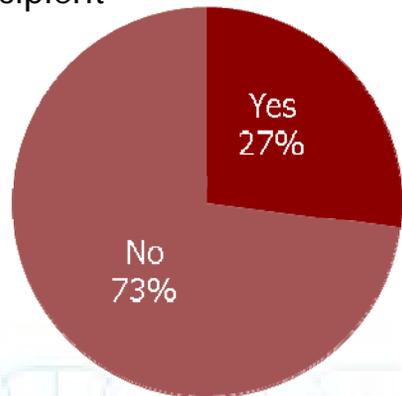
N=125

## Type of Disability Insurance Received

Long Term Disability Insurance	12%
SSDI	59%
Both	11%
Other (VA, Employer)	18%

Nine percent of caregivers and 27 percent of recipients receive disability insurance.

Recipient



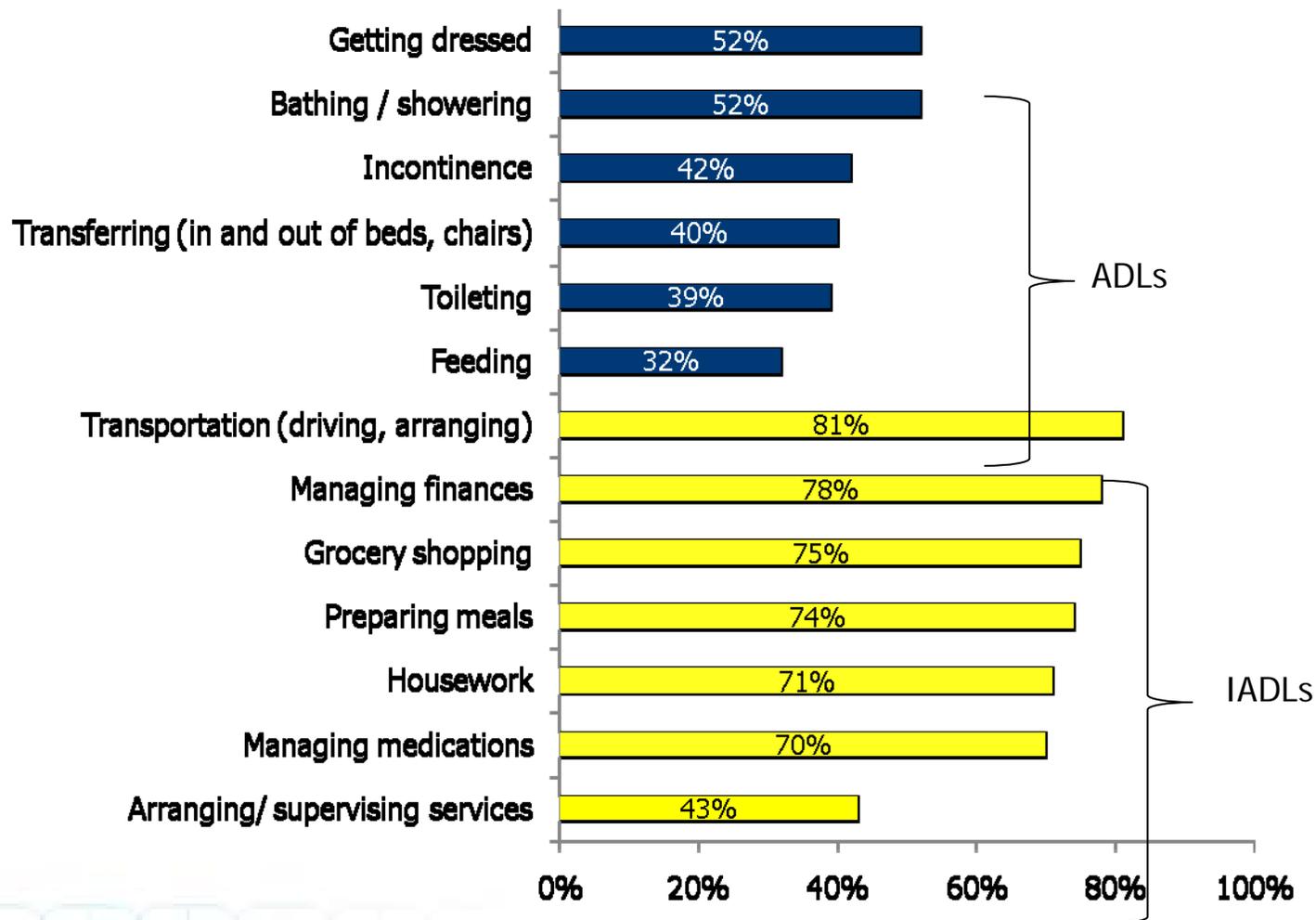
N=370

Long Term Disability Insurance	2%
SSDI	70%
Both	16%
Other (VA, SSI, State)	12%

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Assistance Provided by Caregivers

On average, caregivers helped with 2.6 of 6 Activities of Daily Living (ADLs), and 4.9 of 7 Instrumental ADLs (IADLs).

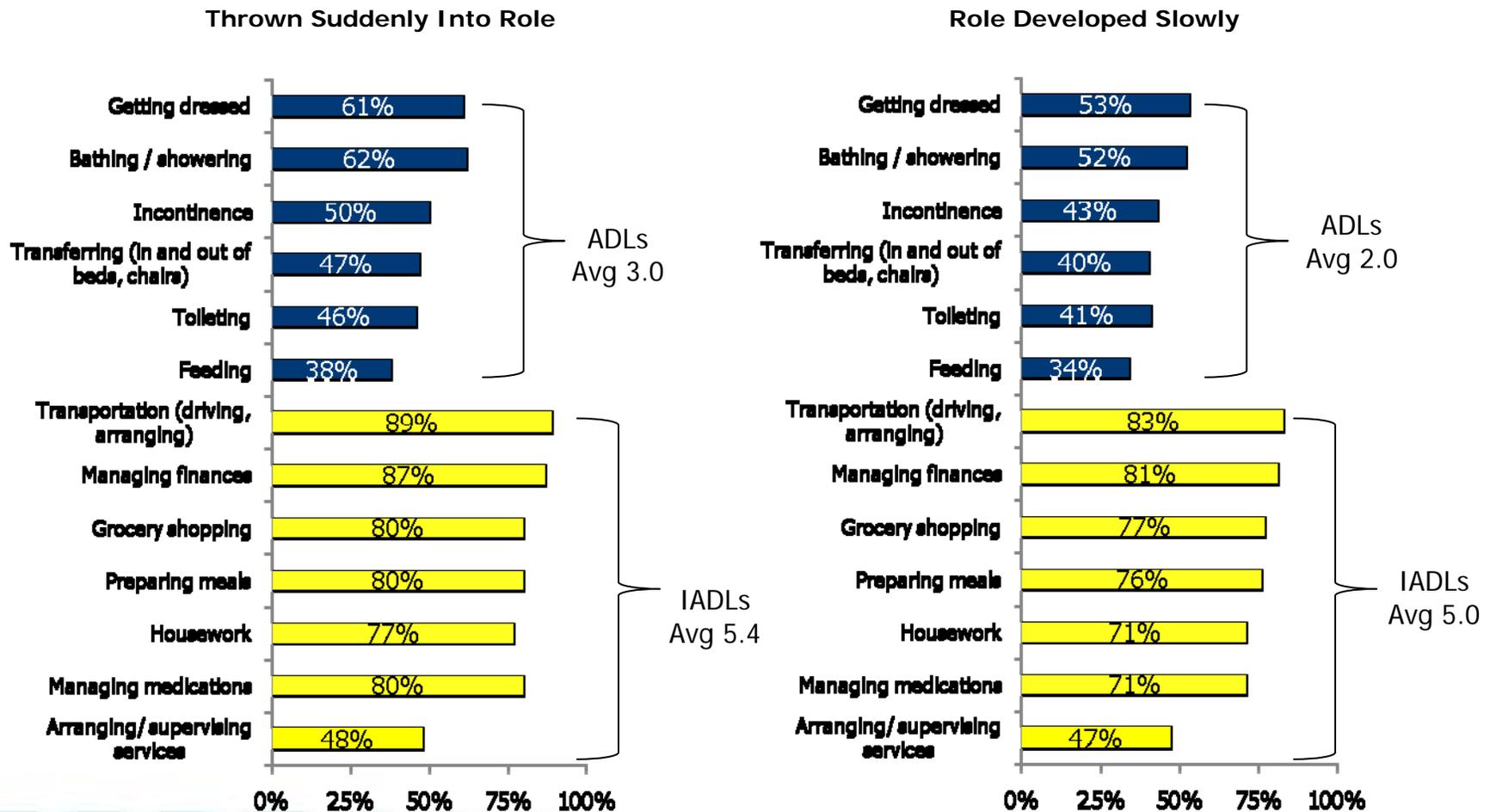


Q: With which of the following do you assist your care recipient? (Select as many as apply)

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Assistance by Evolution of Caregiving Role

On average, caregivers who were thrown suddenly into their role performed more ADLs (3.0 v. 2.0) and slightly more IADLs (5.4 v. 5.0) than caregivers whose role developed slowly.



Q: With which of the following do you assist your care recipient? (Select as many as apply)

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Providing More ADL Assistance

In addition to those caring for those with debilitating life-long conditions, parents and spouses are more likely to provide more IADL assistance.

Avg. # of ADLs helping with (Overall= 2.6 of 6)	Providing More ADL Assistance	Providing Less ADL Assistance
<b>Who care for?</b>	Child 3.2 Spouse or partner 2.7	Parent 2.4, Sibling 2.1 Grandparent 2.1
<b>Where recipient lives?</b>	Caregiver home 3.0	Assisted living 1.5, Care Recipient Home 2.0
<b>Age of recipient</b>	18 to 24, 3.3, 25 to 34, 3.0 34 to 44 2.9	75+ 2.5, 45 to 54, 2.4,
<b>Primary diagnosis</b>	Muscular Dystrophy 5.2 ALS 4.4, Cerebral Palsy 4.4 Spinal disease/damage 4.0 Birth defects 3.2, MS 3.2	Cancer 1.7, Heart disease 1.7 Atrial fibrillation 1.3 Mental illness 1.3 Osteoporosis 1.0 Chronic pain 0.7
<b>Years as caregiver</b>	5+ years 3.0	2 years or less 2.1
<b>Caregiving role</b>	Suddenly thrown into it 3.0	Will grow 2.0
<b>Caregiving help</b>	Primary with help 3.1	One of several 1.9, Helper 1.6
<b>Employment status</b>	Full-time family caregiver 4.1 Unemployed 3.2	Full-time employed 2.4, Disability 2.2

Source: 2011 NFCA/Allsup Family Caregiver Survey

# Providing More IADL Assistance

In addition to those caring for those with debilitating life-long conditions, spouses are more likely to provide more IADL assistance.

Avg. # of IADLs helping with (Overall= 4.9 of 7)	Providing More IADL Assistance	Providing Less IADL Assistance
<b>Who care for?</b>	Spouse 5.3	Grandparent 3.9
<b>Where recipient lives?</b>	Caregiver home 5.5	Assisted living 2.7
<b>Age of recipient</b>	65 to 74 5.2	Under 18 4.1
<b>Primary diagnosis</b>	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	Chronic pain 4.2 Mental illness 4.2 Osteoporosis 4.3 Atrial fibrillation 4.8 Cancer 4.8
<b>Years as caregiver</b>	5+ years 5.3	Less than a year ago 4.8
<b>Caregiving role</b>	Suddenly thrown into it 5.4	Developed slowly 5.0
<b>Caregiving help</b>	Primary with help 5.4, Sole caregiver 5.4	Help others 3.0
<b>Employment status</b>	Full-time family caregiver 6.1, Unemployed 5.7, Student 5.5	Employed full-time 5.0, Homemaker 5.1

Source: 2011 NFCA/Allsup Family Caregiver Survey

# NFCA/Allsup Family Caregiver Survey

## **Methodology**

The NFCA/Allsup Family Caregiver Survey was an online survey of 1,579 Family Caregiver (FCG) 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.

## **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](http://www.thefamilycaregiver.org)

## **About Allsup**

Allsup is a nationwide provider of Social Security disability, Medicare and Medicare Secondary Payer compliance services for individuals, employers and insurance carriers. Founded in 1984, Allsup employs nearly 800 professionals who deliver specialized services supporting people with disabilities and seniors so they may 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 <http://www.allsup.com>

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