

HIP Health Plan of New York
2004 Member Survey About Caregiving

Medical and Quality Informatics
February 14, 2005

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EXECUTIVE SUMMARY

To help HIP in better understanding the needs of its members who are caregivers, HIP conducted The 2004 Member Survey About Caregiving. A one page self-administered questionnaire was used to ask about members' experiences with helping and/or taking care of sick or disabled family members or friends.

In total, 6,112 individuals responded to the survey and 53% of them indicated that they are caregivers.

Of the 3,222 survey respondents who are caregivers, most of them:

- Help their sick or disabled family or friends with:
 - housework, laundry, meals, or grocery shopping (93%)
 - bathing, dressing, eating, going to the bathroom, or walking (67%)
 - taking prescription medicine through pills, injections, inhalers, intravenous drips, infusion pumps, suppositories, etc. (63%)
- Spend 11 hours or more per week helping/taking care of their sick or disabled family members or friends (49%)
- Help just one sick or disabled family member or friend (69%)
- Help family members or friends who have the following health conditions:
 - Arthritis (39%)
 - Diabetes (33%)
 - Heart Disease (27%)
- Report that other family members or friends, besides them help with caregiving (53%)
- Have been a caregiver for 5 years or longer (41%)
- Are female (69%)
- Are currently employed on either a full or part-time basis (48%)
- Rate their own overall health as good, very good, or excellent (67%)

BACKGROUND

HIP Health Plan of New York recognizes that caregivers, while playing an enormous role in our society, are often the “silent patients,” who too often do not receive the assistance and support their role requires. The Integrative Wellness department of HIP developed the Care for the Caregiver Initiative to bring focus and attention to the needs of those who provide care to a family member, friend, or neighbor.

The Care for the Caregiver Initiative aims to:

- Facilitate community based organizations in the effort of bringing to their constituencies the awareness of the important and often unconsidered role of caregivers and the need for each caregiver to realize that in order to help another, he or she must care for himself or herself first.
- Use the theatrical presentation, “Caring for You, Caring for Me,” produced in partnership with Plays for Living, Inc., to aid in the acceptance that caregiving is a role that often masks the hidden patient (the caregiver) and leads to many present and future difficulties, health issues and burdens for the caregiver.
- Provide discussions, literature, other resource materials, and links on the *hipusa.com* Web site to other related organizations offering assistance, guidance and support for caregivers.
- Create an atmosphere in which caregivers can come to understand and accept that in order to “care for you...I must first care for myself.”

SURVEY PROCEDURES

To help HIP in better understanding the needs of its members who are caregivers, HIP conducted the 2004 Member Survey About Caregiving. With input from the Integrative Wellness department, the Medical and Quality Informatics department developed a one page self-administered questionnaire to ask about members’ experiences with helping and/or taking care of sick or disabled family members or friends. (*Appendix A contains a copy of the questionnaire.*)

The questionnaire along with a postage-paid reply envelope for returning the completed survey to HIP were included in the Summer 2004 issue of the HIP’s member newsletter, HIP Today, which was sent to 487,603 members. In addition, members and non-members had the option of answering the survey on HIP’s Web site *hipusa.com*.

Data entry and tabulation of the survey responses were completed by Essex Tabulating Company. Web responses to the survey were accepted until January 18, 2005 and paper responses were accepted until January 21, 2005.

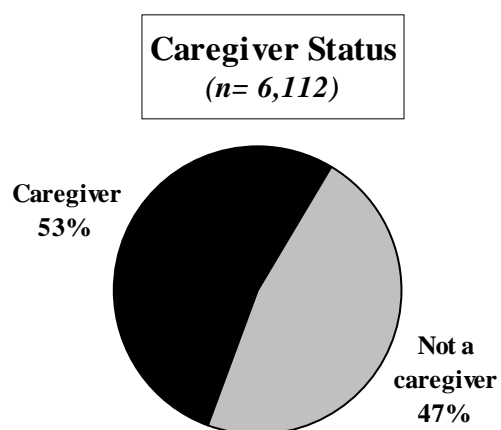
SURVEY RESULTS

In total, 6,112 individuals responded to the 2004 Member Survey About Caregiving. Of those individuals:

- 6,084 completed a paper questionnaire
- 28 completed the survey on HIP's Web site
- 6,106 are HIP members
- 6 are not HIP members

Caregiver Status

Overall, 53% of the 6,112 individuals who completed the survey indicated that they are a caregiver for sick or disabled family members or friends.

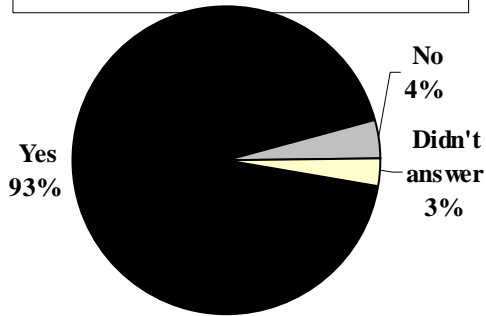


Caregiving Tasks Performed

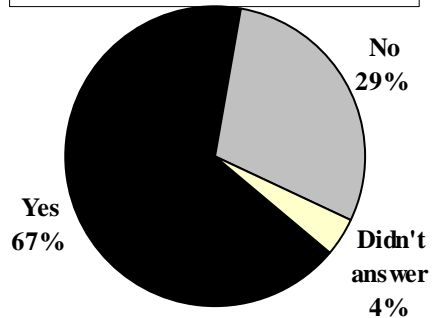
The 3,222 survey respondents who are caregivers were asked to indicate which caregiving tasks they perform for their sick or disabled family members or friends. As shown on the next two pages:

- The vast majority of the caregivers (93%) help with housework, laundry, meals, or grocery shopping.
- Approximately two thirds of the caregivers help with:
 - Bathing, dressing, eating, going to the bathroom, or walking (67%)
 - Taking prescription medicine through pills, injections, inhalers, intravenous drips, infusion pumps, suppositories, etc. (63%)
- Approximately a quarter of the caregivers (27%) help with changing medical dressings or bandages
- Approximately a fifth of the caregivers (19%) help with using special medical equipment (*e.g., oxygen, feeding tubes, home dialysis, catheters, etc.*)
- Approximately a tenth of the caregivers (9%) report that they perform “other” caregiving tasks such as:
 - Manage finances, pay bills, do paperwork
 - Take/escort/drive to medical and non-medical appointments/errands
 - Help with wheelchairs/walkers/canes/Hoyer lifts or other ambulatory aids

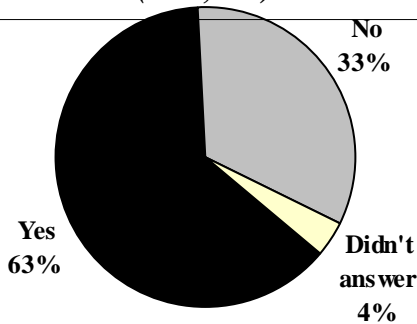
Helps With Housework, Laundry, Meals, or Grocery Shopping?
(n= 3,222)



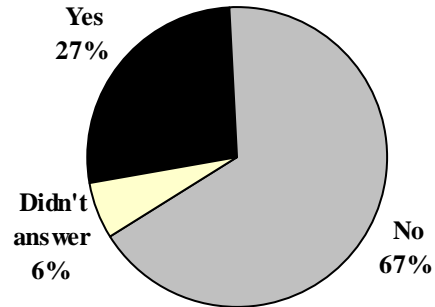
Helps With Bathing, Dressing, Eating, Going to Bathroom, or Walking?
(n= 3,222)



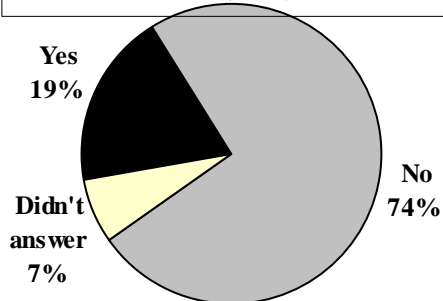
Helps With Taking Prescription Medicine (e.g., pills, injections, inhalers, etc.)?
(n= 3,222)



Helps With Changing Medical Dressings or Bandages?
(n= 3,222)



Helps With Using Special Medical Equipment (e.g., oxygen, feeding tubes, catheters, etc.)?
(n= 3,222)



“Other” Caregiving Tasks Performed*
(n= 3,222)

Manage finances, pay bills, do paperwork	2%
Take/escort/drive to medical appointments	2%
Take/escort/drive to non-medical appointments/errands	1%
Help with wheelchairs/ walkers/canes/Hoyer lifts or other ambulatory aids	2%
Testing/reading of glucose/sugar, blood pressure, etc.	1%
Monitoring medical care/appointments/drugs/prescriptions	1%
Changing diapers/colostomy bags, commode care	1%
Physical therapy, massaging, exercise, body care	1%
Provide companionship, keep company, visit	***
Miscellaneous tasks**	1%
Does not perform “other” caregiving tasks	91%

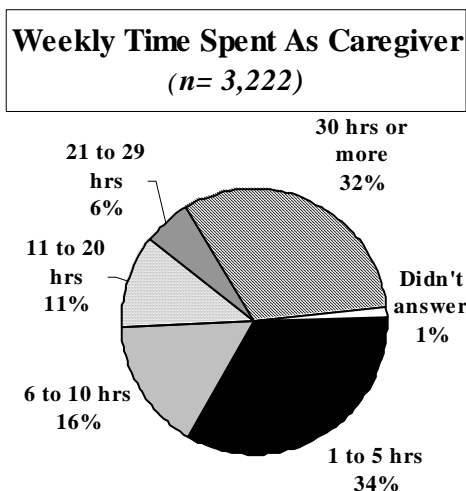
* Some respondents gave more than one answer

** Represents individual tasks, each of which was mentioned by less than 0.5% of respondents

*** Less than 0.5% of respondents

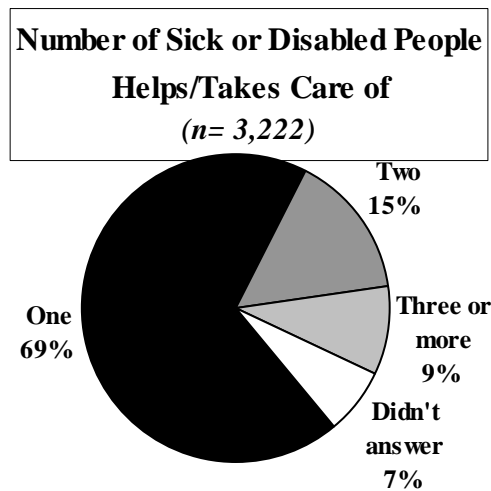
Amount of Time Spent on a Weekly Basis on Caregiving

Approximately half (49%) of the caregivers spend a total of 11 hours or more per week helping/taking care of sick or disabled family members or friends, with approximately a third (32%) of the caregivers indicating that they spend 30 hours or more.



Number of Family Members and/or Friends Caregiver Helps/Takes Care of

The majority of the caregivers (69%) indicate that they help/take care of just one sick or disabled family member/friend. For the vast majority (96%) of those 2,199 caregivers, the one person they help/take care of is an adult.



Health Conditions of Sick or Disabled Family Members/Friends

As shown in the table on the next page, when caregivers were asked what health conditions their sick/disabled family members/friends have, the most frequently mentioned conditions were:

- Arthritis (39%)
- Diabetes (33%)
- Heart Disease (27%)
- Alzheimer's (18%)
- Dementia (18%)
- Cancer (15%)
- Asthma (14%)
- Mental Illness (13%)
- Respiratory Disease (13%)

Health Conditions of Sick/Disabled Family Members/Friends (*n*= 3,222)*

<i>Musculoskeletal System and Connective Tissue Disorders</i>	
Arthritis	39%
Multiple Sclerosis	2%
Hip/back/knee/leg pain/injured/broken	1%
Osteoporosis	1%
Other musculoskeletal system and connective tissue disorders **	1%
<i>Mental Disorders</i>	
Alzheimer's	18%
Dementia	18%
Mental illness	13%
Other mental disorders**	1%
<i>Circulatory System Disorders</i>	
Heart disease	27%
Stroke	5%
High blood pressure	3%
Other circulatory system disorders**	1%
<i>Endocrine/Metabolic Disorders</i>	
Diabetes	33%
Other endocrine/metabolic disorders**	***
<i>Cancer</i>	
	15%
<i>Respiratory System Disorders</i>	
Asthma	14%
Respiratory disease	13%
Other respiratory system disorders	1%
<i>Nervous System/Sense Organs Disorders</i>	
Blind, impaired vision	2%
Glaucoma	1%
Deaf, ear problems	1%
Parkinson's	2%
Cerebral Palsy	1%
Paralysis	1%
Other nervous system/sense organs disorders**	1%
<i>Infectious/Parasitic Diseases (e.g., HIV/AIDS, etc.)</i>	
	4%
<i>Genitourinary System Disorders</i>	
Kidney/renal disease	2%
Other genitourinary system disorders**	***
<i>Digestive System Disorders</i>	
	1%
<i>Congenital Abnormalities (e.g., Downs Syndrome, etc.)</i>	
	1%
<i>Miscellaneous</i>	
Disabled, unable to walk, in a wheelchair	3%
Recovering from surgery	1%
Old age, aging	1%
Other Miscellaneous**	2%
Didn't answer	7%

* Some respondents gave more than one answer

** Represents individual health conditions, each of which was mentioned by less than 0.5% of respondents

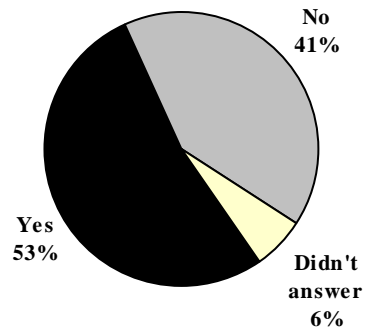
*** Less than 0.5% of respondents

Others Who Provide Caregiving

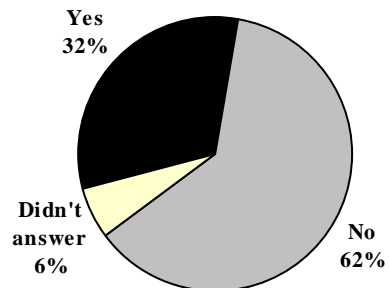
The respondents who are caregivers were asked to indicate whether others also help or take care of the family members or friends that the respondent helps. As shown on the next page:

- The majority of the caregivers (53%) report that other family members or friends, besides them help with caregiving
- Approximately a third (32%) of the caregivers report that professional in-home health care workers (*e.g., home health aides, nurses*) help with caregiving
- About a fifth or less of the caregivers report that the following help with caregiving:
 - Professional housekeeping workers (18%)
 - Professional health care workers in a hospital, skilled nursing facility, or nursing home setting (16%)
 - Volunteers from community outreach organizations (*e.g., Meals on Wheels, etc.*) (14%)

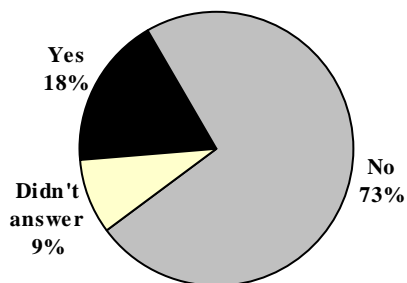
**Other Family Members or Friends
Provide Help?**
(n= 3,222)



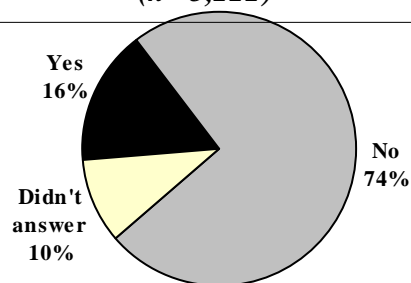
**In-Home Health Care Workers
Provide Help?**
(n= 3,222)



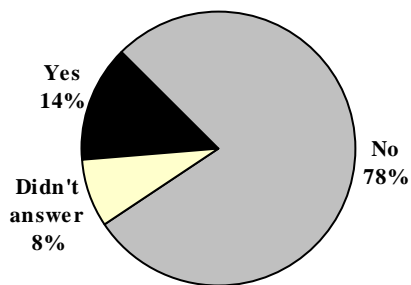
**Professional Housekeeping
Workers Provide Help?**
(n= 3,222)



**Health Care Workers in Hospital,
Skilled Nursing Facility or
Nursing Home Provide Help?**
(n= 3,222)

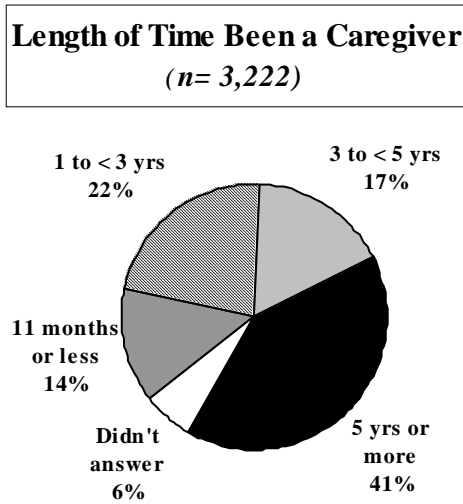


**Volunteers From Community
Outreach Programs Provide Help?**
(n= 3,222)



Length of Time Been a Caregiver

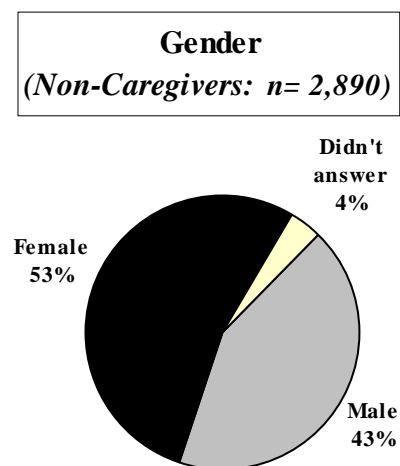
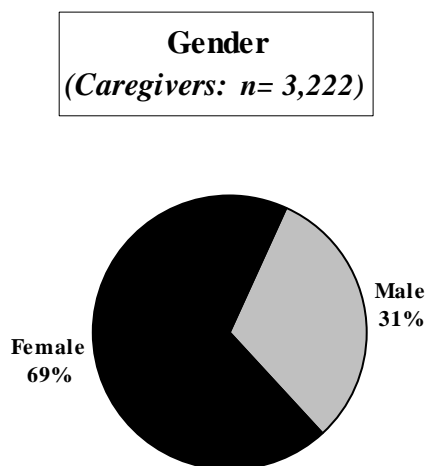
Most of the survey respondents who are caregivers (41%) have been a caregiver for 5 years or longer.



RESPONDENT DEMOGRAPHICS

Gender

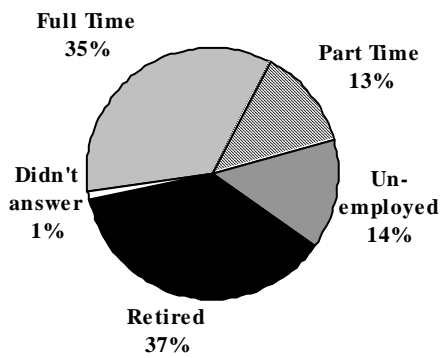
- More than two thirds (69%) of the survey respondents who are caregivers are female.
- Survey respondents who are caregivers (69%) are statistically significantly more likely to be female than are respondents who are **not** caregivers (53%).



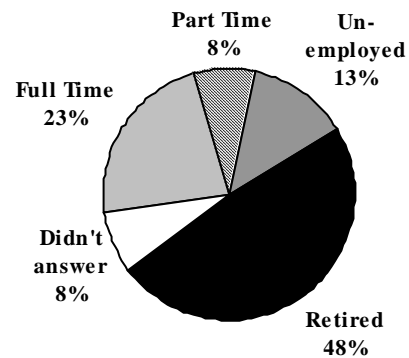
Employment Status

- Almost half (48%) of the survey respondents who are caregivers are currently employed on either a full or part time basis.
- Respondents who are **not** caregivers (61%) are statistically significantly more likely than respondents who are caregivers (51%) to indicate that they are not currently employed. (i.e., are unemployed or retired).

Employment Status
(Caregivers: n= 3,222)



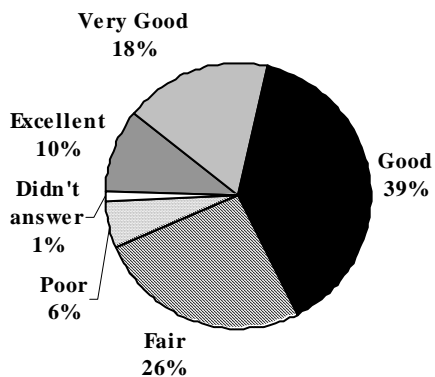
Employment Status
(Non-Caregivers: n= 2,890)



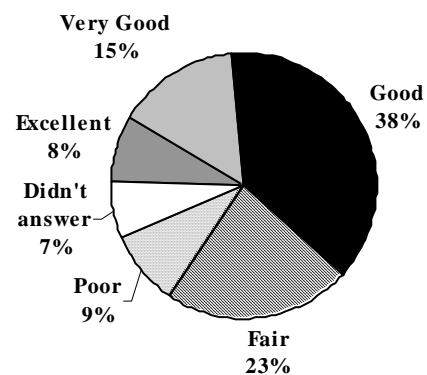
Overall Health Status

The majority of survey respondents who are caregivers (67%) as well as the majority who are **not** caregivers (61%) rate their own overall health as good, very good, or excellent.

Overall Health Status
(Caregivers: n= 3,222)



Overall Health Status
(Non-Caregivers: n= 2,890)



APPENDIX A: QUESTIONNAIRE



HEALTH PLAN OF NEW YORK

MEMBER SURVEY ABOUT CAREGIVING

The following questions ask about your experiences with helping and/or taking care of sick or disabled family members and friends. For each question, please check the box that most closely describes your experience.

- 1) Do you help any **sick or disabled** family members or friends with any of the following?
- | | <u>Yes</u> | <u>No</u> |
|---|--------------------------|--------------------------|
| a) Housework, laundry, meals, grocery shopping | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Bathing, dressing, eating, going to the bathroom, walking | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Taking prescription medicine through pills, injections, inhalers, intravenous drips, infusion pumps, suppositories, etc. | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Changing medical dressings or bandages | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Using special medical equipment (e.g., oxygen, feeding tubes, home dialysis, catheters, etc.) | <input type="checkbox"/> | <input type="checkbox"/> |
| f) Other (PLEASE EXPLAIN) | <input type="checkbox"/> | <input type="checkbox"/> |
- _____

- 2) Approximately how many hours in total do you usually spend **each week** helping and/or taking care of **sick or disabled** family members or friends?
- Zero (**PLEASE SKIP TO QUESTION 7**)
 - 1 to 5 hours
 - 6 to 10 hours
 - 11 to 20 hours
 - 21 to 29 hours
 - 30 hours or more

- 3) How many adult, and how many child, **sick or disabled** family members or friends do you help and/or take care of?
- # of Adults: _____ # of Children: _____

- 4) Thinking about the **sick or disabled** family members or friends you help and/or take care of, do any of the following people also help them or take care of them?
- | | <u>Yes</u> | <u>No</u> |
|--|--------------------------|--------------------------|
| a) Other family members or friends, besides you. | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Volunteers from community outreach organizations (e.g., <i>Meals on Wheels</i> , etc.) | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Professional housekeeping workers | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Professional in-home health care workers (e.g., <i>home health aides, nurses</i>) | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Professional health care workers in a hospital, skilled nursing facility, or nursing home setting | <input type="checkbox"/> | <input type="checkbox"/> |

- 5) Thinking about the **sick or disabled** family members or friends you help and/or take care of, which of the following health conditions do they have? (**PLEASE CHECK AS MANY AS APPLY**)

<input type="checkbox"/> Alzheimer's	<input type="checkbox"/> Heart disease
<input type="checkbox"/> Arthritis	<input type="checkbox"/> HIV/AIDS
<input type="checkbox"/> Asthma	<input type="checkbox"/> Mental Illness
<input type="checkbox"/> Cancer	<input type="checkbox"/> Respiratory disease
<input type="checkbox"/> Dementia	<input type="checkbox"/> Other (PLEASE EXPLAIN)
<input type="checkbox"/> Diabetes	_____

- 6) For approximately how long have you been helping and/or taking care of your **sick or disabled** family members or friends?

- 11 months or less
- 1 to less than 3 years
- 3 to less than 5 years
- 5 or more years

- 7) What is your gender?
- Male Female

- 8) What is your employment status?
- Full time Unemployed
- Part time Retired

- 9) In general, how would you rate **your** overall health now?
- Excellent Good Poor
- Very good Fair

- 10) Do you want to receive regular communications and information from HIP's Care for the Caregiver Initiative?

Name: _____

Address: _____

E-mail: _____

Please fold this questionnaire on the dotted lines. The survey has a postage-paid return address and can be dropped in any mailbox. Thank you for your help!