

## **Summary Results – Survey of Caregivers in Tompkins County - 2003**

As part of the ongoing "Community Conversation on Caregiving," a survey of caregivers was taken in the winter of 2003. The survey was distributed in various forms, including the Ithaca Journal, the Senior Circle, the Office for Aging website, and through direct mail. A total of 225 people completed the Caregiver survey. Because this was not a scientific survey done through random sampling, we cannot use the results to make generalizations about all caregivers in Tompkins County; however, the results do provide us with useful information about the characteristics and needs of those caregivers who responded.

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### **I. Who Are the Caregivers?**

The majority of respondents were adult children caring for their aging parents (61%), followed by those caring for their spouse or partner (19%), friend or neighbor (10%) or other relative (10%). Over three-quarters of the respondents (76%) stated that they were the primary caregiver, that is the one most involved in providing care for the person. Additionally, 20% of those who responded were also caring for children under age 18.

Respondents were of a wide variety of ages, with 73% under the age of 65. Over three-quarters of the respondents were female (77%). Respondents had a wide variety of income and educational levels. Sixty-three percent of respondents were employed outside the home, with 46% employed full-time and 17% employed part-time. Finally, most caregivers who responded lived either in the same home as the care receiver or less than 20 minutes away.

### **II. For Whom Are the Caregivers Providing Care?**

The majority of respondents are providing care for people age 70 or older (91%), and the majority of care receivers are women (60%). Most care receivers are living in their own home or apartment (71%). Respondents indicated that care receivers had a number of medical conditions, the most common being arthritis, heart problems and dementia, and 69% of people had more than one medical condition. The majority of respondents (71%) indicated that the care receiver has a health care proxy or living will.

### **III. The Tasks of Caregiving**

Respondents provided a wide variety of tasks for the care receivers, the most common being grocery shopping, transportation, help with bills and regular phone contact. The caregivers who responded provide these tasks from as little as few times a month to several hours every day. An estimate of the total number of hours of unpaid care provided by this sample of 225 people over a one-month period is 14,726. Many respondents have provided care for a number of years; the majority of which have provided help for between 0-4 years (42%), though a sizeable number have provided care for over 10 years (18%).

#### **IV. Stresses and Rewards of Caregiving**

Of those caregivers who responded to the survey, 40% stated that others were providing them with enough relief from caregiving tasks, 27% stated that they were not receiving enough relief, and 33% stated that they had nobody else to help them. When asked whether others were doing their fair share to help with caregiving, 50% stated "yes, as best as they can," while another 30% stated "no, they are not," 11% stated they "have no other friends/family to help," and 9% stated that tasks were divided evenly. Among the stressful aspects of caregiving, respondents tended to cite "emotional stress" most often (74%), followed by "not enough time for myself" (55%), and "sadness about losses" (38%). Those who report that other family and friends are not doing their fair share to help with caregiving cite these stressful aspects of caregiving with greater frequency than overall respondents. Caregivers also cited the effects of caregiving on employment, with 79% of respondents who were employed stating that they had to go to work late, leave work early, or take time off due to caregiving.

Among the positive aspects of caregiving, respondents tended to cite "helping family" most often (68%), followed by "caring for others" (55%) and "being appreciated" (44%).

#### **Comments from the Caregiver Survey**

Many comments indicated that people need help in finding information about services and need training in providing care to their care receiver. Below are ones that seemed particularly relevant.

##### Additional training requested

- Would welcome Alzheimer's Association in Ithaca for additional education, support and services. Need "close circle" education materials in order to have more involvement from friends and non-proximate family.
- They need a program to TRAIN personal care aides for Home Health Care – NO such program available! Only for nursing homes. Also an employment agency for such!
- Evening support group for people whose care receiver has dementia; more medical info on research findings on dementia; workshops on how to assist dementia patients who are close family members.
- Is there a place to get training in bed baths, etc. for an invalid? Also needed – training in how to observe and present information to doctors. I am amazed at how much they rely on untrained family members in evaluating their patients. They don't even tell you what you're supposed to be looking for, what's a problem that needs to be reported, what kind of information they'd like you to give them.
- We have learned through counseling to set our limits and make the care receivers aware of them, and they have begun to take on more responsibilities themselves that they are able to do and this has lightened our stress.

### Need information about services

- There are some services in the community that I think people are not made aware of, and it's important that they information get out to them. The more the caregiver knows, the better for everyone involved.
- In general, Ithaca offers more than most. I deeply appreciate what's available here. It would be wonderful if new caregivers got a packet of "information" with forms they'll be needing i.e.: P.O.A., medical release – so we can get information after doctor visits, health care proxy, information about taxes, forms to take your receiver off mailing lists and call lists, etc.
- I need lots of help. What services are available and at what costs?
- Informed help. I feel we have been victimized by providers who are looking for customers! Bad/wrong/misleading information has cost us thousands. PLUS, loss of service or poor service that was so important for a stroke survivor.
- Legal questions answered – often finding out information after it's a problem. Would be nice to know ahead of time what to expect with money and legal issues.
- We've just started seeking out information on what help is available
- Many hours on the phone with agencies produced meager results.
- The specific services available in Ithaca should be more known to those individuals in need; and there must be better coordination among the various agencies in Tompkins County that are providing the services to the aged, with limitation of costs to the care receiver a primary concern.