



In Support of Caregivers

A Publication of the Caregivers' Resource Center and Alzheimer's Support Unit at the Tompkins County Office for the Aging

Fall 2004

Vol. 16, Number 3

In this Issue:

- ⇒ Fall Workshop Opportunities
- ⇒ How Are You Doing?
- ⇒ News and Notes
- ⇒ Long Distance Caregivers
- ⇒ "Please Try It" Initiative
- ⇒ Alzheimer's Notes

Dear Readers,

A few years ago, I was reluctant to put links to Internet sites in this newsletter since most readers did not have Internet access or were reluctant to take advantage of the new technology. Now many, if not most, readers are accessing the Internet from their home regularly. Twenty percent of you are receiving this newsletter in its on-line version.

I would like to bring to your attention other resources that may be of interest to family caregivers that are available on-line at the web site of the Tompkins County Office for the Aging. If you go to our home page at www.tompkins-co.org/cofa and click on "publications" you will be directed to a page with this chart:

Agency Publications

Resource Guides for Tompkins County Seniors	Additional Office for Aging Publications
Financial and Legal Resources for Seniors	Caregivers' Newsletter, Summer 2004
Health Programs for Seniors in Tompkins County	Caregivers' Newsletter, Spring 2004
Housing for Seniors in Tompkins County	Caregivers' Newsletter, Winter 2003
Leisure Time Activities for Seniors	Caregivers' Newsletter, Fall 2003
Long Term Support Services in Tompkins County	Medications Guide
Resources for Caregivers in Tompkins County	Millennium Report
"Grandparents Raising Grandchildren" Guide	You May Qualify...

As you will note, in addition to back issues of this caregivers' newsletter, you can access all the resource guides published by the Office for the Aging. They are revised and updated periodically. (The "Housing for Seniors" guide was just revised this July.) All of these publications are also available in paper form if you prefer to be mailed or pick up a copy. Finally, please also be sure to check out another valuable local web site of interest to family caregivers that is maintained by the Tompkins County Adult and Long Term Care Services: www.tompkins-co.org/dss/ltc.

David Stoyell, Caregiver Coordinator

Fall Support Groups

The Caregivers' Resource Center facilitates the following groups. Call 274-5492 for details.

Alzheimer's & Other Dementia Caregiver Support Group

- Open to those caring for loved ones with Alzheimer's or other cognitive impairments.
- Meets on the 4th Tuesday each month (Sept. 28, Oct. 26, Nov. 23)
- 1:00 - 2:30 PM in the Office for the Aging Conference Room (320 N. Tioga St., Ithaca)

Caregivers of Adults with Developmental Disabilities

- Will meet on the 3rd Thursday evening of the month (location and program varies; in September, group picnic at Stewart Park)
- For information on the group and upcoming gatherings, call Trina Schickel, 274-5491.

Parkinson's Group

- Open to Parkinsonians and their Caregivers.
- Meets on the 3rd Wednesday of the Month (Sept. 15, Oct. 20, Nov. 17)
- 2:00 PM - 3:30 PM at Cooperative Extension, 615 Willow Ave., Ithaca
- Co-sponsored by Cornell Cooperative Extension of Tompkins County.

Groups Sponsored by Other Local Agencies:

The Tompkins County Stroke Support Group



(for both stroke survivors and caregivers of stroke survivors) meets at the Finger Lakes Independence Center, 3rd Wednesday of every month from 1:00 – 2:30 PM. For information, call Joe Zanfordino, 227-0143.

Support Group for Caregivers of People with Cancer- meets on the 1st Wednesday of the month from Noon to 1:30 PM at the Hospicare Center. Call Susan Merryfield, 272-0212.

Local Caregiver Services

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging

Contact:

David Stoyell (CRC Coordinator: 274-5492)

Trina Schickel (Project CARE: 274-5491)



The Caregivers' Resource Center & Alzheimer's Support Unit offers family caregivers information and consultation services, support groups, workshops, this newsletter, and a lending library of books and videos on caregiving topics. Stop by or call for an appointment.

Volunteers from *Project CARE* give caregivers a needed break and help out in other ways as needed. Trina may also be able to arrange for paid home care services to support stressed caregivers through Long Term Care Services. To discuss the program, give Trina a call.



In-Home Counseling & Respite Service

Family and Children's Service

Contact: Lisa Kendall: (277-8081)



A caregiver counselor will visit family caregivers and help them work through complex caregiving issues or for emotional support. This program also offers grant-funded home health aide respite service to give caregivers a needed break.

Adult Day Program

Longview Adult Day Community

Tuesdays, Wednesdays, Thursdays, 9 am-3 pm

Contact: Marilyn Strassberg (375-6320)

Adult day programs offer older adults companionship along with planned social and recreational activities. It often provides a break from caregiving and time for other matters. Includes lunch and snacks. Possible partial scholarship for low-income applicants.

Fall Workshops offered by the Caregivers' Resource Center at the Cooperative Extension Education Center 615 Willow Avenue, Ithaca

(The following workshops are offered free of charge. Pre-registration is encouraged, but not required. Contact David Stoyell for details or to register, 274-5492 or e-mail: dstoyell@tompkins-co.org.)

“An Overview of Family Caregiving Concerns”

Speaker: Patty Lynott, Ph.D., IC Gerontology Institute

Wednesday, September 22, Noon – 1:30 PM



Dr. Lynott is a sociologist who teaches a course on “Families and Aging” at Ithaca College and has been doing research for 20 years on family relationships. This workshop will bring you up-to-date on research about family caregiving and afford participants a chance to relate this research to their particular caregiving situations. Community resources that can help address caregiving concerns will be outlined at the end of the workshop.



“Caring for Aging Parents”

Speaker: David Stoyell, Caregivers' Resource Center

Thursday, October 21, 7:00 – 8:30 PM

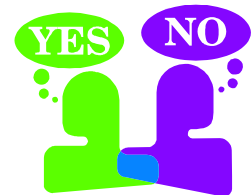
Mr. Stoyell is the Coordinator of the Caregivers' Resource Center at the Tompkins County Office for the Aging. This is an evening workshop for those concerned about aging parents or other older relatives, whether they live nearby or far off. Issues to be addressed include: “Getting the Whole Family Involved,” “When Your Loved One Resists Care,” “Balancing Work and Caregiving” and “Identifying Resources that Can Help.”

When the Diagnosis is Alzheimers: Communication Skills for Care Partners

Speaker: Lisa Kendall, CSW, Family and Children's Service

Tuesday, November 9, Noon – 1:30 PM

(repeated Thursday, November 11, 6:30 – 8:00 PM at Walden Place, Cortlandville)



Communication is essential in caregiving situations, and can be extra-challenging when your loved one has Alzheimer's or any related dementia. This class will help you understand more effective ways of communicating with older adults with memory problems, and includes a brief overview of dementia and how it affects thinking and communication skills. Participants will explore common barriers to successful communication, become more aware of feelings and their role in communication, learn effective communication techniques, and discover strategies for discussing sensitive caregiving issues. Local and national resources for caregivers and their loved ones will also be identified in this relaxed and informative session. Ms. Kendall is the Caregiver Counselor and Caregiver Respite Program Coordinator at Family and Children's Service in Ithaca.

(To register or for information on the Nov. 9 session, call David Stoyell at 274-5492. To register or for information on the Nov. 11 session at Walden Place, call Lisa Lunas, 756-8101.)

More Programs of Interest to Caregivers

Distinguished Speakers

Gary Myers, Ph.D.

October 21 at 7:30 PM

Unitarian Church of Ithaca, 306 N. Aurora

Gary Myers is a psychologist and minister on the faculty of the medical school at the University of Southern Illinois. The Tompkins County 'End of Life Coalition' is sponsoring his talk. His talk will be on the topic of **transformation and communication at the end of life**. Free.

Karl Pillemer, Ph.D.

December 2: at 7:00 p.m.

Ithaca College: Emerson Suites/Phillips Hall

Karl Pillemer is Co-Director of the Cornell Gerontology Research Institute and Professor in the Department of Human Development at Cornell. His presentation is titled: *Solving the Crisis in Long-Term Care: Why Focusing on the Workforce Matters Most*. Free.

Lifelong "Housing Fair"

October 6, 1:00-5:00 PM

at Lifelong, 119 W. Court St.

will include:

- ◇ **Exhibitors** representing the full range of housing options available to older adults
- ◇ **Presentation** by Vera Prosper, Senior Policy Analyst at the New York State Office for the Aging on 'Housing Alternatives and Senior Preferences'
- ◇ **Presentations** on the 'Status of Senior Housing in Tompkins County' and on 'In Home Services to Help You Age in Place'
- ◇ **Demonstration** of Assistive Technology Devices for Aging in Place
- ◇ **Instruction** on Using the Internet to Find Resources.

IC Gerontology Institute Workshops

These workshops provide continuing professional education to those working with older adults.

Family caregivers may also find them helpful. Each workshop costs \$15 or \$10 for those 60+ and retired. For further information on any of these programs, please visit www.ithaca.edu/aging or call Terry Beckley at (607) 274-1967.



September 8: 1:30 – 4:30 p.m.

Understand and Working with Low Vision

Laura Henry and Robert Hanye, Association for Vision Rehabilitation & Employment, Inc., Binghamton, NY.

October 6: 1:30 – 4:30 p.m.

Evaluation and Treatment of Memory Impairment: What to Remember

Fred Marshall, MD, Assistant Professor of Neurology, University of Rochester Medical School.

November 10: 1:30 – 4:30 p.m.

Doorway Thoughts: Crossing the Threshold to Cultural Competence

Sharon A. Brangman, MD, Division Chief, Geriatrics, SUNY Upstate Medical University, Syracuse, will examine multi-cultural considerations in caring for the aged.

How Are You Doing?

Professionals who have extensive experience working with caregivers agree on five basic strategies to help prevent stress from having destructive effects. If you are feeling “caregiver stress,” check how you are doing on each of the following:

1. Setting Realistic Goals & Expectations

How realistic are your expectations? Do you find yourself saying “I should be able to do...*(something more than is possible)*.” Women caregivers are particularly vulnerable to “should’s.” Unrealistic promises can also impair one’s ability to make the best decisions for all concerned. When you believe you should be able to do more than you can realistically, you may feel guilty or depressed.

Check one:

- I have set realistic caregiving goals.*
- I need to work on clarifying my expectations of myself.*
- It’s impossible for me to keep my expectations of myself realistic.*

2. Establishing Your Limits

Once you recognize your limits, you must “establish” them, meaning you must communicate them to your family and your relative in need of care. It also means it is all right to say “no.” It may be painful, but to not do so will eventually result in more pain. Discussing limits is usually easier if you share information about other ways which your relative’s needs can be met at the same time you talk about your limits.

Check one:

- I have communicated my limits.*
- I need to have a frank conversation with _____ and _____.*
- I couldn’t possibly tell them what needs to be said.*

3. Asking for and Accepting Help

Is it difficult to ask for assistance. When you request support, are you specific enough so people know exactly what you

want. Do you refuse offers of help, but feel exhausted? Some view asking for help as a sign of inadequacy or failure. Actually, it is just the opposite. Reaching out for assistance before you are beyond your limits is an important trait of a strong individual. It also helps ensure quality care for your family member. Being a martyr benefits no one.

Check one:

- I have let others know how they can help.*
- I need to let people know how to help.*
- I’m stressed, but I can’t see how anyone can help.*

4. Taking Care of Yourself

This one has three parts:



- a. Expressing your feelings—it is important that you have someone with whom you can talk openly about your situation and your emotions (a friend, relative, support group or counselor),
- b. Maintaining your physical health (proper sleep, exercise, and regular physicals are sometimes neglected),
- c. Taking time for yourself—respite in your day, in your week, and an occasional vacation. Time away that you can look forward to and that can “recharge your batteries.”

Check one:

- I get regular breaks that renew me.*
- It’s clear I need to plan more breaks from caregiving.*
- No one else can do what needs to be done or he/she won’t accept care from others.*

5. Involve Other People

If you checked the second choice on some of the above, plan to talk with family and friends. Also, call us at the Caregivers’ Resource Center (274-5492) to explore local resources that can help.

If you checked the third choice on some of the above, ask about caregiving counseling options or other professional guidance available to help you make the difficult choices necessary for your health and quality care for your loved one.

News and Notes

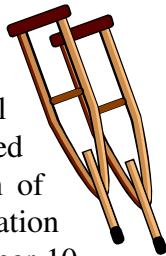
Insurance Help

The New York State Insurance Department has developed a new web site which it calls "Insurance Help for the Seriously Ill and their Caregivers." It seeks to provide the comprehensive insurance information needed by families when illness strikes including details of health insurance rights and how to exercise these rights to ensure proper access to health insurance coverage. Visit the site at www.insurancehelpny.com. For helpful explanations of Medicare, Medigap policies and Medicaid, visit <http://hiicap.state.ny.us>.



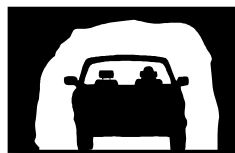
Stroke Rehab Program

Those who have experienced a stroke, and have already been discharged from a formal rehabilitation program, are invited to participate in the fall session of Ithaca College's Stroke Rehabilitation Program, September 8 – December 10, 2004. It consists of 12 hours of therapy per week and may include occupational therapy, physical therapy, therapeutic recreation and speech-language therapy. For more information, call Catherine Gooch at (607) 375-6312 or e-mail her at cgooch@ithaca.edu.



Conversation with Older Drivers

The Hartford Insurance Company has a guide for families preparing for a conversation with an older driver about possible adjustments or curtailing of driving: www.thehartford.com/talkwitholderdrivers
A printed copy of a guide for families concerned about the safety of an older driver,



When You Are Concerned, can be obtained by calling the Caregivers' Resource Center at the Office for the Aging, 274-5492.

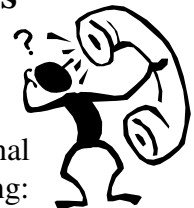
Hiring In-Home Help

The Family Caregiver Alliance has a good fact sheet for those hiring in-home help, including assessing needs, working out a job description, pros and cons of hiring through an agency or privately, finding and interviewing applicants if hiring privately, and making home care situation work. The fact sheet, *Hiring In-Home Help*, can be found on-line at www.caregiver.org (click on fact sheets and publications for an extensive list of fact sheets on family caregiving topics). A copy of this fact sheet can also be sent by the Caregivers' Resource Center (274-5492).



Long Distance Caregivers

The 13-page report, *Miles Away: The MetLife Study of Long-Distance Caregiving*, can be found at the website of the National Alliance for Caregiving: <http://www.caregiving.org/>
You can read a summary of the findings on page 7 of this newsletter.



Caring Conversations

A helpful workbook to help individuals and their families share meaningful conversation while making practical preparations for end-of-life decisions can be viewed or downloaded from the Center for Practical Bioethics: <http://www.midbio.org/mbc-cc.htm>.
You can also receive a paper copy of this 16-page booklet from the Caregivers' Resource Center (274-5492).



Long Distance Caregivers Also Face Challenges

Some may suppose that long distance caregiving isn't difficult because direct care is not being provided on a day-to-day basis. A recent study suggests that those of you who are finding it difficult to do caregiving at a distance are not alone. 1,130 long-distance care providers participated in an on-line survey conducted by Zogby International, a polling and market research firm. Following is a summary of some of the study's key findings confirming that living at a distance can make care provision a complex and difficult challenge.



KEY FINDINGS

The Caregiving Situation

- (Despite an average distance of 450 miles and 7.23 hours of travel time one-way, long-distance caregivers reported substantial regular personal contact with the person they were helping; 51% reported visiting at least a few times a month.
- (Nearly one-fourth (23%) of the long-distance caregivers reported they were the only or primary caregiver.
- (Nearly three-quarters of the respondents were helping their loved ones with instrumental activities like transportation, shopping, managing finances or cooking and were spending 22 hours a month on this help.
- (Almost half reported that they were managing needed services and spending the equivalent of nearly one full day a week doing so.

- (Long-distance caregivers most often depend upon a sibling who lives near the care recipient.
- (Nearly 80% of these care providers were working either full or part-time.

Effect on Work

- (More than four in ten had to rearrange their work schedules in order to take care of their caregiving responsibilities, more than a third (36%) reported missing days of work, and 12% took a leave of absence.
- (Both men and women were equally likely to have rearranged their work schedules, left early or come in late to work, taken an unpaid leave, or to have considered changing employers.
- (Women were more likely than men to report that they missed days of work and/or moved from full-time work to part-time work.

Financial Contributions

- (Long Distance Caregivers spend an average of \$392 per month on travel and total out-of-pocket expenses.
- (Distance is a factor in the total out-of-pocket expenses reported by respondents. Those who live between 1 and 3 hours away from the care recipient spend an average of \$386 per month on travel and direct expenses for items needed by the care recipient; those who live more than 3 hours away spent an average of \$674 per month.
- (For the relatively small group of respondents (nearly 10%) who also paid for services the care recipient needed, women reported spending on average \$751 a month compared to men who spend an average of \$490 a month.

Assistive Technology for Aging in Place

Many people are not knowledgeable about, nor have access to, the latest technology that is available that might assist them in staying in their own home. While some of these assistive devices are very high tech and expensive others are very low tech and very inexpensive.



New “Please Try It Room”

A *Please Try It Room* was recently opened at the Finger Lakes Independence Center (FLIC) in Ithaca. This room is stocked with various devices that individuals might want to try out. These devices are available for loan for a period of two weeks. Then, if the device is helpful, the individual can get the device either through a catalog or purchased locally. Information on where to get these items will be readily available at the *Try It* room. The *Please Try It Room* is open during regular business hours, 9:00 a.m. – 5:00 p.m. weekdays, 215 5th Street, Ithaca.

\$10,000 in New Equipment

The *Please Try It Room* is part of a larger effort being promoted by FLIC, the Tompkins County Office for the Aging and Ithaca College Occupational Therapy Department to assist people to “age in place” with the help of assistive technology. Thanks to a grant received from the National Association of Home Builders Research Center, the Office for the Aging is funding the purchase of \$10,000 in new assistive equipment for the *Please Try It Room*. These new purchases will be devices that enable older adults to remain as independent as possible in their homes.

Some of the items already in the *Please Try It* room are rubber doorknob extension, uni-turner, supergrip button hook, long reach bathroom cleaner, stand up dust pan and brush set, trolley cart, kitchen roll-about, long reach duster, magic opener, hot pan

gripper, aluminum check writing guide, EZ page magnifier, bedrail, EZ shoe on, helping hand tray, shoe remover, dialtalk pocket talk phone dialer, double spatula, vegetable chopper, reacher, easi-reader bookstand, sock aid, shake awake, photo phone, big button cordless telephone, pocket talker, jumbo seven day pill reminder, boil alert to name just a few of the items available.

Traveling Exhibitions

In addition to the *Please Try It Room*, a traveling display will be taken to gathering places in the county of older adults and caregivers of older adults. Occupational Therapy students from Ithaca College with the support of FLIC staff and OT Professor, Carol John, will demonstrate various pieces of equipment and will also be able loan out the equipment, again for 2 weeks, to try out. This process will allow individuals to actually see if the item works and if they should indeed purchase it.

Some of the assistive technology will be on display at:

LIFELONG HOUSING FAIR

Wednesday, October 6, 1:00 – 5:00 PM
Lifelong, 119 W. Court St.

FLIC’S 6TH ANNUAL TECHNOLOGY FAIR

October 19, 9 a.m. to 12 noon
Holiday Inn, downtown Ithaca

SENIOR CITIZEN’S FAIR

Thursday, October 28, 8:30 a.m.– 1:00 p.m.
 (“Please Try It” display: 10:00 – Noon)
Titus Towers, 800 S. Plain St.

On-line Guide

Plans are also in the works to develop an online guide for Tompkins County residents to help them identify and obtain assistive equipment appropriate to their needs. In the meantime, for an idea of what kinds of assistive devices exist, visit www.abledata.com, sponsored by the U.S. Department of Education).

Alzheimer's Notes

More Area Seniors Living with Loved Ones Having Dementia

The 2004 Tompkins County Senior Needs Assessment found that 4.8% of respondents were living with someone 60+ in the household with Alzheimer's or other dementia. This number is up from 2.2% in the last survey conducted in 1995.

The increased numbers may in part be due to earlier diagnosis and treatment of dementia with the availability now of medications developed in the 1990's and early 2000's.

Second Annual Tompkins County Memory Walk Sunday, September 19 Alterra Garden Path (Rt. 96 and Bundy Rd.)

Registration is at Noon; the walk itself begins at 1:00 PM. Funds raised benefit the mission of the Alzheimer's Association of Central New York including their educational programs, advocacy, 24-hour helpline, and other services. The proceeds also support the national efforts of the Alzheimer's Association to advance research aimed at prevention and treatment of Alzheimer's and other dementias.

Walk as an individual or as part of a team in the 1st Annual Tompkins County Memory Walk. Contact Ellen Reuben locally at 277-0005, or e-mail her at ereuben@alzcnny.org to be sent the Memory Walk materials.

If you would like to walk as part of a group associated with the Alzheimer's Support Group at the Caregivers' Resource Center, contact David Stoyell at 274-5492.

Counseling for Alzheimer's Spouses Keeps the Blues Away

A recent study confirmed a message often conveyed in this newsletter—that counseling and support can go a long way toward reducing the risk of depression. A newly-released study of 406 men and women caring for a spouse with Alzheimer's found that those who had received counseling and help from a support group had lower rates of depression over three years.



The study found that the benefits last over the long term, and “seem to hang on even after the spouse dies or enters a residential care facility,” according to the leader author, Dr. Mary Mittelman, of the NYU School of Medicine. Mittelman also found that including other family members in counseling sessions can prove key when there are disagreements about care.

See page 2 of this newsletter for information on local caregiver counseling and caregiver support groups.

Parting One-Liners

From the sublime....

“I’m not afraid of storms, for I’m learning to sail my ship.”

-Louisa May Alcott

“The whole point of getting things done is knowing what to leave undone.”

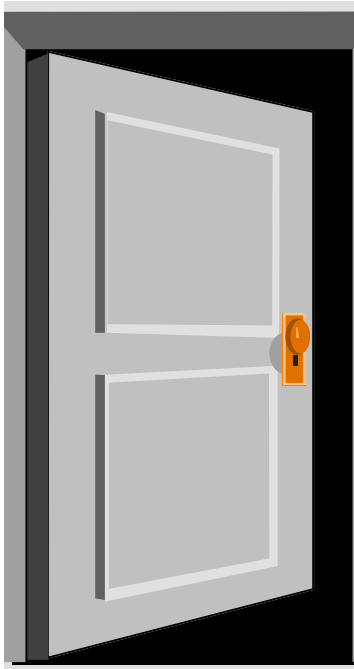
-Lady Stella Reading

To the ridiculous....

“I intend to live forever. So far, so good.”

“... and I used to think I was indecisive, but now I’m not so sure.”

-unknown



**The Caregivers' Resource Center
and Alzheimer's Support Unit**

Please call or visit us **at the Tompkins County Office for the Aging in the County Courthouse basement, 320 North Tioga Street in Ithaca. Open weekdays, 8:30 am-4:30 pm.**

Telephone: (607) 274-5492

E-mail: dstoyell@tompkins-co.org

Office for the Aging website: www.tompkins-co.org/cofa

Long Term Care website: www.tompkins-co.org/dss/ltc

A useful national website: www.caregiver.org

National Alzheimer's Association: www.alz.org

This newsletter is made possible in part by a grant from the NYS Office for the Aging. Edited and published by David Stoyell, Caregiver Coordinator.

This newsletter can now also be received by e-mail or viewed on our website.

If you prefer to be sent a notice when a new issue appears on our website, or to have it sent as an e-mail attachment, please contact the Caregivers' Resource Center. Note that articles marked "reprinted with permission" may not be further reproduced, except for private use, without permission of the original publisher. Other material in this newsletter may be freely copied with proper credit given to its original source.

Caregivers' Resource Center
and Alzheimer's Support Unit
Tompkins County Office for the Aging
320 North Tioga Street
Ithaca, NY 14850