



In Support of Caregivers

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

Summer 2005

Vol. 17, Number 2

In this Issue:

- ⇒ **Your Changing Role**
- ⇒ **Organizing Key Documents**
- ⇒ **Excessive Heat Events**
- ⇒ **Relating to Family Members**
- ⇒ **Heart Failure & Palliative Care**
- ⇒ **Simple Pleasures Exercises**

Dear Reader,

The vast majority of the calls to the Caregivers' Resource Center come from adult children who are concerned about, or caring for, their frail elderly parent(s). If I went only by the number of calls I received, I would assume that not many older adults were engaged in caring for their spouses and other relations. Of course we know that is not true.

In fact, the 2004 County-wide Senior Needs Assessment conducted by the Tompkins County Office for the Aging found that 7.6% of respondents (60 and older) were caring for someone who was also 60 or older in or near Tompkins County. Another 3.8% reported caring for a senior more than an hour away. Almost 6% were caring for another older person in their own household.

These results can be combined to estimate that 2,070 Tompkins County seniors are providing care for another older person. But the reality is that many of those who are caring for spouses are going it alone to the detriment of their health and the well-being of their loved one. Vowing to love "for better or for worse" and "forsaking all others" should not mean forgoing help when the caregiving gets tough. It never used to mean that in generations past when extended family lived near by and pitched in when illness struck a parent, grandparent, aunt or uncle.



Today with smaller extended families that may be living hundreds of miles away, older adults who are caregivers need to take advantage of community based resources if they are to care for their loved ones (and themselves) as well as they can.

Give us a call with your family caregiving issues and concerns (274-5492).

David Stoyell, Caregiver Coordinator

Summer Caregiver 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
June 28, July 26, August 23
- 1:00 - 2:30 PM in the Office for the Aging Conference Room (320 N. Tioga St., Ithaca)

Parkinson's Support Group

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

Caregivers of Adults with Developmental Disabilities

- Does not meet during the summer. Meetings resume in September (location and program varies). For information on the group, call Trina Schickel, 274-5491.

Groups Sponsored by Other Local Agencies:

Multiple Sclerosis Caregiver Group (for parents, spouses and others caring for family members with MS) meets the third Tuesday of every month at the Holiday Inn, Ithaca. Contact Patricia Phelps for information, 539-6477.

The Tompkins County Stroke Support Group (for 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.



An evening-time **Alzheimer's Caregivers Group** meets at Walden Place in Cortlandville, 2nd Thursday of the month at 7:00 PM. For information, call 756-8101.

Local Caregiver Services

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging

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 David 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. Call Trina to discuss your needs.



In-Home Counseling & Respite Service

Family and Children's Service

Call: Lisa Kendall or Donna George (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.

Your Changing Role

Whatever your age, you are a caregiver if you provide care that helps a frail elderly or disabled person live at home. In fact, 80% of all our nation's caregiving is provided by informal caregivers such as you. Caring for a relative or friend may be something you never expected or wanted. It can develop slowly or happen suddenly. Few are trained to be caregivers, and there is much to learn to make caring easier.



At various times you may be manager, organizer, observer, consumer, and legal, financial and medical planner. It's certain that your role will change constantly as your care receiver's condition worsens or improves.

Problems You May Face

Health problems of the elderly can be many and complex. Physical illnesses may be difficult to detect, as symptoms may be diminished, absent, delayed in onset or not characteristic of the illness in a younger person.

Find out about the illness or disability. Doctors and other health professionals can tell you the medical and behavioral signs, the length of illness or disability, and if your responsibilities may change. Sensory changes can lead to physical difficulties. Poor vision, for example, may result in a fall. Reduced hearing can be misconstrued as confusion or negative behavior. While such losses can have a profound effect on a person's ability to remain independent, helpful adjustments can often be made.

Ask medical professionals about what your care receiver's condition may mean for you! For instance, people with declining mental faculties may progress from minor forgetfulness to total lack of memory. Therefore, the amount and

type of care or supervision you provide may change as the condition changes.

Your Reactions as a Caregiver

A confusing mix of emotions is normal—many caregivers have similar feelings. Recognize your emotions and deal with them. You may be troubled by feelings that you didn't expect. For example, at the same time you feel love and concern, you may feel hostility or resentment; anger at your elderly parent or spouse; sadness or grief; helplessness and possibly shame at your helplessness.

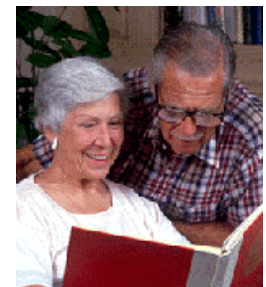
Care for Yourself

Caregiving can be both satisfying and stressful. You may feel pressure from your job or other family demands. Know the warning signs that you are reaching a breaking point:

***Shortness of temper * sleeplessness * physical problems such as loss of appetite, headaches, fatigue, shortness of breath and dizziness * withdrawal from people close to you * financial problems * lack of interest in normal leisure activities**

*** inability to accept help from others**

Another person depends on you! If you are not in good health, that person may suffer.



Respite Care

Finding help begins with you. Taking a break from caregiving is one of the most important things you can do to sustain your caregiving ability and desire. Respite care, or taking time out from caregiving gives you time to spend with friends or alone, time to relax, take a vacation or engage in a hobby or sport. The person you are caring for can also benefit from seeing and being around others while you are taking your break. Medical experts agree that frail elderly or disabled people should be encouraged to do as much for themselves as possible. Involvement with others is an excellent way to spur interest in and work towards independent activity. ***Call the Caregivers' Resource Center to find paid and volunteer respite options in Tompkins County.***

Set Goals

Setting goals helps. What do you hope to accomplish by providing care? Develop a “job description” and think realistically about what you can, can’t or won’t do.

Others Also Care

Involve other family members and friends and neighbors with giving care, and keep them involved. Clear-cut family roles can help everyone know what they should do for the ill or disabled person. Family conferences are useful in developing goals, making long-term plans for the care receiver, for sharing information and feelings, and for planning

emergency or vacation back-up assistance for the primary caregivers.



Be specific in your requests for help. Consider what each individual can do, such as providing help while you’re gone, or spending a few hours a week talking or reading to your care receiver. Be realistic about how long you’ll need this help. Consider a “trial period” so all parties can see how it works.

(Excerpted from “Time to Care,” a brochure published by the NY State Office for the Aging.)

Organizing Your (or Your Care Receiver’s) Key Documents

Sooner rather than later, you should develop an elder kit that features all of your or your care receiver's personal, financial and key medical information for easy reference. This is a way to keep key records organized and readily accessible whenever you need them in a hurry. Here are a few tips for what you should keep in the Elder Kit, found on the Fannie Mae website: www.fanniemae.com

Personal information should include:

- Full legal name, legal residence, birthdate and social security number.
- Location of birth certificates, marriage license and divorce decree, if appropriate
- Naturalization or citizenship papers
- Adoption papers
- Names, addresses and phones of all children
- Education and military records
- List of employers and dates of employment
- Religious affiliation and church/synagogue/clergy names, addresses and phone numbers.
- Names and addresses and phone numbers of close friends
- Wills and durable power of attorney documents

Key medical information should include:

- Names, addresses and phone numbers of all doctors, pharmacies and emergency services including local hospital emergency rooms
- Health/medical history of each parent
- Medicare and health insurance numbers and information
- List of all recent doctor visits, medical exams and test results and current health condition. Make sure to note any special medical conditions and allergies.

Financial information should include:

- Real estate deeds, apartment leases, titles, liens
- Social security earnings records
- Sources of income
- Investments and insurance policies
- Bank accounts
- Location of safe deposit boxes and contents
- Tax returns for past six years
- Auto information: original documents from the dealer, title, registration and insurance
- Names and account numbers of credit cards
- Inventory of personal property



News and Notes

Drug Treatment Up for Older Adults

Admission for substance abuse treatment increased by 32% among older adults over the eight-year period, 1995-2002, according to a federal study. Opiates, the second most frequent reason for treatment admissions after alcohol, increased from 6.8% to 12%. Opiates include prescription pain medications. For a confidential discussion of possible substance abuse concerns in older adults, contact Al Alfaro at Cayuga Addition Recovery Services, 273-5500.



Geriatric Outreach Program

The Geriatric Outreach Program is operated by the Tompkins County Mental Health Clinic to meet the unique needs of older adults with mental health concerns. When an older client cannot (or is unwilling) to come to the clinic, services can be provided in the home or community settings. Services include mental status assessments and treatment, including counseling and/or medications coordinated with the client's personal physician. Contact Dan Kornblum, Team Coordinator, 274-6230.



What's Good for the Heart Is Good for the Head

A recent NY Times article reported on various studies showing that the same strategies for reducing the risk of cardiovascular disease are also effective in equipping the brain to better protect itself against the encroaching damage of Alzheimer's. "It is not that circulatory disease causes Alzheimer's, but if the brain lacks a healthy flow of blood through the vessels..., it is less able to fight off the damage associated with (Alzheimer's)." Thus, the study concludes, neglecting any of the following raises the risk of developing dementia symptoms: high



cholesterol and blood pressure, excess weight, smoking, lack of exercise.

Medicare Implementation

D

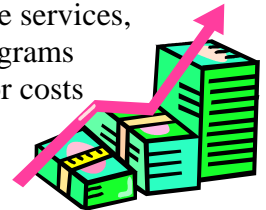


The new prescription drug benefit through Medicare will begin on January 1, 2006. It will be called Medicare Part D. Low-income Medicare recipients should be getting "Low Income Subsidy" letters mailed directly to them starting at the end of May. ***This letter should not be ignored.*** Persons "deemed eligible" for the subsidy will not have to pay the new Medicare D premium or deductible and will have low copayments (ranging from \$1 -\$5).

Enrollment in Medicare Part D and plan selection will begin in the fall. Those not eligible for the full subsidy will need to decide at that time whether or not enrolling in Medicare Part D makes sense for them. EPIC (the New York State Prescription Drug Program) will continue to exist and its eligibility requirements will remain the same. More on the relationship between EPIC and Medicare D will be printed in the next issue of this newsletter. If you have questions, call the HIICAP program at Lifelong (273-1511) or the Office for the Aging (274-5482).

Paying for Eldercare Tuesday, July 12, 7:00 – 8:30 PM Lifelong (119 W. Court St., Ithaca)

David Stoyell, Aging Services Specialist at the Office for the Aging, will speak about the cost of various kinds of long-term care services, what insurance and public programs might pay for, and planning for costs that might fall to you or loved ones when paid services are needed.

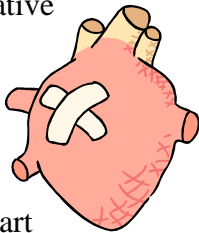


Pre-registration is appreciated, but not required. Call David Stoyell at the Office for the Aging-5492.

Note: See p. 9 for upcoming workshops and conferences of interest to family caregivers of loved ones with Alzheimer's or other dementia.

Heart Failure & Palliative Care

Hear Failure is a chronic and progressive disease that results in a weakened heart that has to work harder. It is the fastest-growing disease in the U.S.. Heart Failure is treated with a continuum of care. The care starts out being curative but becomes more palliative as the disease progresses.



The goal of palliative care is to provide the highest quality of life possible through symptom control and pain management. Heart disease is categorized according to a person's ability to perform activities of daily life (ADL's). Class IV or late stage Heart Failure has several signs and symptoms. These include oxygen dependence, fatigue, diminished quality of life, anxiety, depression and an inability to function. As a person's condition worsens, the patient and family may want to consider hospice.

If a person has some or all of the symptoms of Class IV Heart Failure, the requirements for enrolling in hospice would be met. The goal of hospice care is to provide pain and symptom control along with other supportive measures. The services are designed to enhance the quality of the person's remaining life. The care is provided by a team of doctors, nurses, chaplain and social workers, aides, and volunteers. Historically, fewer than 10% of Class IV Heart Failure patients are enrolled in hospice. This is perhaps unfortunate.

For people in an earlier stage, a palliative care consultation may be helpful, and might involve a consult about physical symptoms, counseling for the emotional side of living with a serious illness, or spiritual counseling as people cope with the spiritual aspects of living with a life-threatening illness. In Tompkins County, call Hospicare and Palliative Care Services at 272-0212 or visit their website at www.hospicare.org.

(Adapted from the February 2005 Parish Nurse Newsletter and April 2005 Broome County Caregiver Corner.)

Question and Answer

Q. A reader who is caring for a frail relative in her home asked that we address in this newsletter what she or other readers should do at the time of the death of her loved one. **“Who should I call?” “Does someone need to officially pronounce him deceased?”**

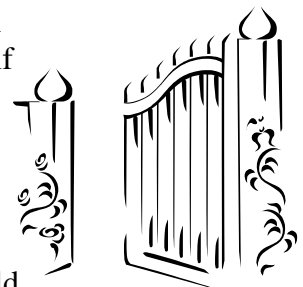
A. We asked Alice Cole, RN, the director of the Tompkins County Health Department, to answer the reader's questions. Her reply:

“It's semi-complicated. If someone is under the care of a licensed or certified home health agency, then the policy varies by agency.

The issue is not necessarily of the pronouncement of death. It's the determination of a natural death (versus a homicide or suspicious death). If someone is not under the care of any agency, then the death is considered “unattended” and law enforcement must be contacted and come to the scene and then contact the medical examiner to determine a cause of death.

If law enforcement can determine that the deceased has been under the regular care of an MD, then that information is related to the medical examiner and taken into consideration (for example, an autopsy then would probably not be ordered).”

Note: Some people call the funeral director first if they have already decided on a funeral home. Funeral homes are used to taking these calls at all times of the day and night. The funeral director would then have them contact law enforcement in the case of an “unattended” death



Health Care Proxies and Living Wills

Guides to preparing advance medical directives, with needed forms, can be obtained by calling the Office for the Aging or online at: www.oag.state.ny.us. Be sure to send a copy of the health care proxy to the hospital most frequently used.

Excessive Heat Events

The best defense against excessive heat is prevention. Reflect ahead of time on the strategy you will use to support your care receiver when oppressive heat arrives.



The following advice is offered by the U.S. Environmental Protection Agency:

- Air conditioning is one of the best protective factors against heat-related illness and death. Even a few hours a day in air conditioning can greatly reduce the risk.
- Electric fans may provide comfort, when temperatures are in the high 90's, fans do not prevent heat-related illness.
- Drink lots of fluids. Don't wait until you are thirsty to drink. If a doctor limits your fluid intake, make sure to ask how much to drink when it's hot.
- Take a cool shower or bath.
- Also, ask your health care provider if medications taken could increase susceptibility to heat-related illness.
- Avoid beverages containing caffeine, alcohol or large amounts of sugar. These drinks cause dehydration.
- Wear light-colored clothing that is loose-fitting.
- Visit at-risk persons at least twice a day. Signs of heat-related illness include hot dry skin, confusion, hallucinations, and aggression. Call 911 if medical attention is needed



Relating to Family Members

Some suggestions offered to primary family caregivers for relating to other family members:

- Be honest about your loved one's illness.
- Educate them about the illness.
- Express your needs as a caregiver.
- Ask for help.
- Accept that some relatives may drift away.
- Nurture supportive relationships.
- Encourage visitors, but ask them to call first.
- Involve children in age-appropriate ways.
- Reassess needs/roles periodically.
- Continue to communicate.

*(Reprinted with permission from the Spring 2005 issue of **Vantage**.)*

Calculator Helps Seniors and Families Examine Reverse Mortgages

An online calculator can now assist you in determining the benefits and costs of a reverse mortgage. Reverse mortgages allow older homeowners to borrow money that does not need to be repaid until they sell or move from their home.

The Reverse Mortgage Calculator allows you to calculate benefits under three types of programs, including the most commonly utilized federally uninsured "Home Equity Conversion Mortgage." To use the service, individuals enter their birth date, estimated home value and zip code and information about any liens on the home or major repairs needed.

To access the calculator, visit www.reversemortgage.org. Counseling about reverse mortgages is available to Tompkins County residents from the Tompkins County Office for the Aging (274-5492).

Dementia Caregiver Pages

Simple Pleasures Exercise

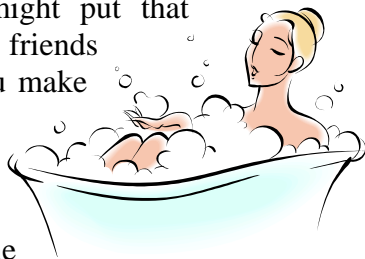
The Eden Alternative™ Principle #6:

Meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health.

In the day-to-day struggle to care for someone with Alzheimer's or a related illness, it is easy to lose sight of meaning in our lives and the lives of those we care for. While all attention is focused on caring for the human body, the human spirit is often neglected. This activity shows how both the human spirit and human body of caregivers and care receivers can be uplifted when we re-discover even the smallest of things that bring meaning to our lives.

1. Think of those things in your life that bring you the most pleasure. Usually these are small, simple daily pleasures. It may be that hot bath and glass of wine in the evening; or watching a sunset; or playing with a pet; or watching children playing; or that first cup of coffee in the morning. Simple pleasures are different for everyone, but each of us has them. They make our day a little better...
2. Ask the elder or individual with dementia to remember those simple pleasures he's had in his life. Make a list.
3. Bring to mind those simple pleasures that bring meaning into your life. Make a list.
4. Take one pleasure that you have given up and one that is no longer in the care receiver's life. Think of how you might put that pleasure back. Talk to friends and family to help you make this possible.
5. Enjoy your simple pleasure again.
6. Now take another one and make that happen. Soon your lives will once again be filled with simple pleasures and with the meaning that is essential to our health.

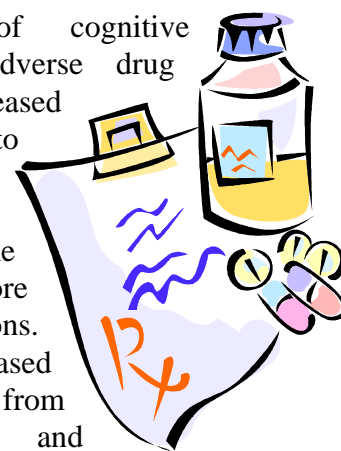
(Reprinted with permission from the Spring 2005 issue of Vantage.)



Impact of Inappropriate Medications

“Decreased cognitive function is sometimes the result of adverse drug interactions, polypharmacy (taking multiple medications) or noncompliance with medications regimens. Unfortunately, once a patient is admitted to a long-term care facility, the dangers of a complex medication regimen do not cease....”

“The consequences of cognitive impairment (due to adverse drug reactions) included decreased ability to socialize and to accomplish activities of daily living, as well as increased caregiver time and potentially more adverse drug reactions. Patients may exhibit increased agitation, and suffer from pressure ulcers, falls, and injuries.”



Unfortunately, when such events occur, additional medications may be provided, yet they may also contribute to cognitive impairment or cause other complications. Minimizing drug loads may improve cognition...”

“It is important for everyone involved in the care of a cognitively impaired patient (health care professionals as well as caregivers) to be able to recognize behavioral problems, determine their source, and to work together as a team to provide optimal care to delay further cognitive decline, and to improve quality of life.”

(Source: Excerpts from an article by Cooper and Burfield in ElderCare, Vol. 5, Issue 1).

Save the date

The 2005 Memory Walk fundraiser for the CNY Alzheimer's Association will be held on Sunday, September 18. More details in the next issue.

Family Caregiver Trainings of Interest to Dementia Caregivers:

Caring for the Person with Alzheimer's Disease

Thursday, June 23
9:00 a.m. - 4:00 p.m
Cornell Cooperative Extension
615 Willow Avenue, Ithaca

A free training offered by the CNY Alzheimer's Association. Program topics include:

- *Medical Overview of Alzheimer's and related dementia's
- *Communication and Behavioral Symptoms
- *Activities of Daily Living and Safety
- *Legal and Financial Planning



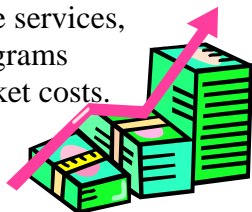
Pre-registration is required. There is no charge. To pre-register, contact the Western Regional Office at 607-272-3491

Note: This program is being held at six locations in Central New York this summer. A similar program at Walden Place in Cortlandville on Saturday, June 11 may be convenient for some readers.

Paying for Eldercare

Tuesday, July 12
7:00 – 8:30 PM
Lifelong (119 W. Court St., Ithaca)

David Stoyell, Aging Services Specialist at the Office for the Aging, will speak about the cost of various kinds of long-term care services, what insurance and public programs might pay for, and out-of-pocket costs.



To register or for information, call David Stoyell at the Office for the Aging, 274-5492.

A Medical Perspective on Alzheimer's Disease

Wednesday, June 15
6:00 p.m. – 7:30 p.m.
Alterra Clare Bridge Cottage
101 Bundy Road, Ithaca

A free presentation with Dr. Jody Stackman, a neurologist with Cayuga Neurological Associates, as the featured speaker.

Appetizers and desserts served.

Offering in conjunction with the Tompkins County Office for the Aging & the Alzheimer's Association.



RSVP to Brad at (607) 351-7857.

Alzheimer's 2005

A Conference for Professionals and Caregivers
Thursday, June 9
8:45 a.m. – 3:00 p.m.
Justin's Grill and Conference Center
Syracuse, NY

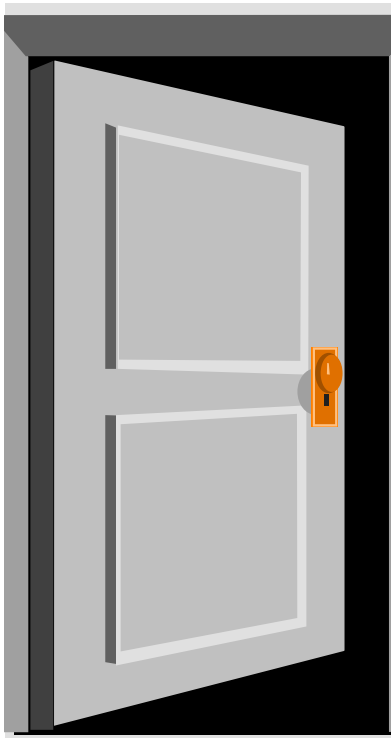
The morning session (9:00 a.m.-Noon) will feature Naomi Feil, MS, ACSW, the creator of *Validation Therapy*.

The afternoon session topics include *Caregiver Planning: A Community Resource Kit* and *Questions for the University Geriatrician's Team*.



Cost: Family Caregiver: \$55.00
Healthcare Professional: \$65.00
(includes course materials and lunch)

Phone: 315-464-5167



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