



In Support of Caregivers

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

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Dear Reader,

We have come to the end of another year. It has been a noteworthy year with the inception of our popular *Powerful Tools for Caregivers* classes. We are grateful for the partnership with Lifelong, the Cayuga Medical Center, Hospicare, and the Department of Social Services which makes these classes possible. We hope to expand the program in 2009 with the addition of more trainers enabling us to offer the classes at more locations.

On a more mundane note, it is time for our annual appeal for *voluntary* contributions to help defray the production and distribution costs of this newsletter. I have enclosed a return envelope for your convenience if you are able to contribute or if there has been a change in your address or caregiving status.

Dave Stoyell
Caregivers' Resource Center Coordinator



----- (detach and mail in envelope provided) -----

Enclosed is a contribution of \$_____ to support production of this newsletter.
(Make checks to "Office for the Aging Newsletter")

I am no longer involved with caregiving. Please remove me from your mailing list.

Name _____ Address _____

City/town: _____ Zip Code _____

(Do you have any comments or suggestions for this newsletter? Write them below or on the back.)

Winter Support Groups

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



Caring for Aging Parents

- Open to those caring for parents or other elderly relatives or friends.
- Meets on the 3rd Wednesday of each month:
(Dec. 17, Jan. 21, Feb. 18)
7:00 – 8:30 PM at Lifelong, 119 W. Court St.
- Sponsored in cooperation with Lifelong

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 of each month:
(Dec. 16, Jan. 27, Feb. 24)
- 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:
(Dec. 17, Jan. 21, Feb. 18)
- 2:00 PM - 3:30 PM at Cooperative Extension, 615 Willow Ave., Ithaca
- Sponsored in cooperation with Cornell Cooperative Extension of Tompkins County

Evening Alzheimer's Group

In addition to the daytime group (above), people caring for loved ones with Alzheimer's or related disorders can also now attend a group that meets at 5:30 PM on the 1st Wednesday of each month (Jan. 7, Feb. 4, March 4). It meets at Lifelong, 119 W. Court St. and is sponsored by the Alzheimer's Association of CNY. For information, call 330-1647.

Local Caregiver Services

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging

David Stoyell, Katrina Schickel, and Marilyn Roberts Chase (274-5482)



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. We may also be able to arrange for paid home care services or short-term respite for stressed caregivers who are having difficulty paying for those services. Call Trina to discuss your needs.



In-Home Counseling & Respite Service

Family and Children's Service

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
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.

Older People Have Real Pain

One of the preconceptions of older age, is that you're supposed to live with aches and pains. According to "*Chronic Pain for Dummies*," this is a preconception also held by some doctors. It can be a particularly distressful form of *ageism*.

Some older adults buy into it themselves. When asked if they hurt, their response might be "who can complain?" or "I'm fine." But if doctors and family members inquire further, they might learn of soreness, stiffness or some other sort of pain they are silently enduring.

The American Geriatrics Society reports that arthritis is the most common cause of pain in older adults. Nerve pain, muscle pain, circulatory problems and shingles are other common causes. Pain is common in our later years, although it is not, and should not, be regarded as normal or inevitable.

Studies have shown that older people are often undertreated for pain. Not only does failure to treat pain lead to discomfort, but neglected chronic pain can cause other problems. Pain is often managed with medications, but there are also alternative and complementary approaches to pain control.

Geriatricians say that narcotics are prescribed too infrequently rather than too often, when needed for breakthrough pain. But they must be taken under the watchful eyes of a physician who can monitor side effects.

Some health conditions can affect the ability of older adults to take their medication safely and effectively. *Vision problems* may cause difficulty in reading prescription labels or differentiate between pills. *Hearing problems* may cause difficulty in listening to advice from doctors and pharmacists. *Cognitive impairment* may cause confusion over whether or not medications have been taken. *Loss of dexterity* may make opening packages or containers difficult.

Older adults may also benefit from alternative or complementary treatment strategies like deep breathing exercises, biofeedback, meditation, massages and exercise programs. Physical therapy may be prescribed. What is most important is that pain is not ignored or undertreated just because someone is older.

Amazingly sometime people think (or perhaps hope) that Alzheimer's patients can't feel pain as sharply as can other aging adults. Alzheimer's patients receive painkillers less often than their peers do. Christopher L. Edwards, PhD, director of the Pain and Palliative Care Center at Duke University in Durham, N.C. Edwards has studied pain in people who are unable to communicate. "We traditionally assume that individuals without verbal ability don't have the same pain we do. That is not correct. These patients do have the capacity for pain. Their pain is relevant, and it is deserving of evaluation and treatment."

Doctors can use a tool called the Pain and Discomfort Scale or PADS. It's a system for evaluating pain based on facial expressions and body movements.

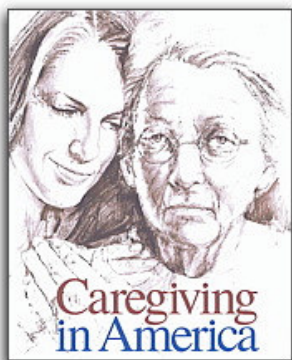


"Caregivers have an incredible capacity -- even beyond doctors -- to know the behavior of the person they are caring for and to look for the times they are in discomfort or pain," Edwards says.

"The trick is to watch the facial expressions and movements of patients when they are not in pain, both during sleep and waking hours. Then, using that as a baseline, be attentive to circumstances where they seem agitated, where eye contact is altered, where there is grimacing or a facial expression indicative of discomfort."

Should We Calculate the “Economic Value” of Caregiving?

According to a recent AARP report, “In 2007, about 34 million family caregivers provided care at any given point in time, and about 52 million provided care at some time during the year. The estimated economic value of their unpaid contributions was approximately \$375 billion in 2007, up from an estimated \$350 billion in 2006.”



The economic value of caregiving exceeded total Medicaid long-term care (LTC) spending in all states, and was more than three times as high in 36 states. Compared with Medicaid home- and community-based service spending, the

economic value of family caregiving was at least three times as high in all states, and more than 10 times as high in 19 states.

In the past we’ve avoided publishing statistics like that in this newsletter because it seemed to imply that that family caregivers are “saving” the taxpayers money. That would be as silly as implying that parents are saving the taxpayers by taking care of their own children rather than handing the responsibility for their care over to the state.

But what these statistics do drive home is that families are still doing most of the eldercare that is taking place in our society. But the “supply and demand of caregiving” has changed radically. With extended families living all over the country, fewer relatives are around to pitch in with the care. With advances in medicine, older adults are living a lot longer with disabilities.

The fact is that it is a lot harder for those who are doing the caregiving to have a healthy balance in their lives. The costs of caregiving to caregivers

themselves are more than a simple accounting of hours and managing competing demands on their time. They include direct out-of-pocket expenses, economic insecurity caused by changes in work patterns, and health effects.

Policy recommendations at both the federal and state levels have been offered to prevent family caregivers from being overwhelmed by the demands placed upon them and to fund more services and supports for them.

Emergency Action Plan

Some tips to prepare your elders for a disaster:

- 1. Collect necessary supplies.** Gather items related to your relative’s health and personal requirements (e.g., extra glasses, hearing aid batteries, hygiene items, etc.).
- 2. Prescription medicines-** keep a supply that can last at least a week.
- 3. Arrange important documents and phone numbers-** including insurance cards, contact information for insurance agent, doctors, non-local relatives and friends.
- 4. Include personal items for comfort.**
- 5. Establish a communications strategy.** Who will be contacted and how.
- 6. Make an emergency plan for pets.** Where will they be taken. Are special pet carriers or harnesses needed? Other items needed by pets.
- 7. Talk about your plan of action** with your family member. If your loved one lives in a residential care facility, learn about what may happen to your loved one if disaster strikes.



Provide Peace of Mind for Your Family

(One of the first things we ask new family caregivers is whether or not their loved one has filled out “advance medical directives” and a durable power of attorney. The following article reminds us that caregivers (and every one over 18) should also complete advance medical directives for themselves. For more information on completing advance directives, visit the website cited at the end of the article or call us at the Caregivers’ Resource Center.)

What will happen if you experience a sudden illness that prevents you from making your own medical decisions? Will your family or loved ones know enough about what you value and believe to feel comfortable making decisions about your care?

Everyone 18 years of age or older should express their health care preferences and end-of-life wishes to family members and their physician and put them in writing in a legal document called an *advance directive*. This discussion and documentation process is known as *Advance Care Planning*, and it will spare your loved ones the emotional burden and turmoil that come with trying to guess what your wishes might have been, particularly during a medical crisis when you can’t speak for yourself.

In 2002, *Means to a Better End*, the first national end-of-life report card, reported that just 15 to 20 percent of Americans had an advance directive. Unfortunately, the completion rate had not increased since Americans were given a right to do so with the 1991 Patient Self-Determination Act. That’s probably because many people believe this is an issue solely for the elderly or the seriously ill. In November 2005, the Pew Center reported that 29 percent of Americans have an advance directive. Experts speculate that this increase likely represents a silver lining to the tragic case of Terri Schiavo that prompted these questions to be openly and thoughtfully discussed.

The reality is that these conversations should begin when individuals are young, healthy and

independent, and they should continue as our life experiences transform our views of what is important, and what we are willing to undergo in terms of medical treatments and interventions.

Advance Care Planning is a process that asks individuals to explore, clarify and put in writing their values, beliefs, goals of care and expectations. It requires them to name a legal spokesperson, and an alternate, who will work best with physicians and health care providers to carry out patient wishes. And it also requires them to complete the necessary legal documents, keep them up-to-date and make them accessible to their spokesperson, provider and others.



Copies of a step-by-step booklet on Advance Care Planning can be obtained free of charge at the Office for the Aging. A new video on traditional advance directives called *Community Conversations on Compassionate Care* along with Five Easy Steps for completing an advance directive can be viewed on-line at www.compassionandsupport.org.

(Source: Article in Sept. 2008 issue of Long Term Care News, by Patricia Bomba, M.D., Vice-president and medical director, Geriatrics for MedAmerica Insurance Company.)

Online Advance Directive Registry

You can now store your NY State Health Care Proxy form and other advance directives on a secure on-line service at:

www.AssuringYourWishes.org

By filing your advance directive on the Assuring Your Wishes registry, you can assure that it will be available to individuals to whom you give your pass code and all health care providers involved in your medical care.

Powerful Tools for Caregivers

Caring for someone with a chronic illness such as dementia, heart disease, Parkinson's disease or stroke can be stressful physically, emotionally and financially. Join us for this six-week educational program designed to provide you with the tools you need to take care of yourself. You will learn to: reduce stress, improve self-confidence, increase your ability to make tough decisions, better communicate your feelings, locate helpful resources and balance your life.

Session I: Mondays: March 30 – May 4
6:00 – 8:30 PM
Old Jail Conference Room
125 E Court St. Ithaca

Session II: Tuesdays: March 31 – May 5
1:30 – 4:00 PM
Sterling House
103 Bundy Rd, Ithaca

Session III: Tuesdays: March 31 – May 5
6:00 – 8:30 PM
Lifelong
119 W Court St, Ithaca

**POWERFUL
TOOLS**
for Caregivers

Each session is a separate class with the same content; they are not interchangeable.

Register for only one by calling or emailing:

Marilyn Roberts Chase at the Office for the Aging: 274-5488 or mroberts@tomkins-co.org

Caregiver Burnout Symptoms

1. Disrupted sleep patterns.
2. Altered eating patterns.
3. Increased sugar consumption or use of alcohol or drugs.
4. Increased smoking or strong desire to start again.
5. Frequent headaches or sudden onset of back pain.
6. Increased reliance on over-the-counter pain remedies or prescribed drugs.
7. Irritability.
8. High levels of fear or anxiety.
9. Impatience.
10. The inability to handle one or more problems or crises.
11. Overreacting to commonplace accidents.
12. Overreacting to criticism.
13. Overreacting with anger toward a spouse, child or older care recipient.
14. Alienation.
15. Feeling emotional withdrawal.
16. Feeling trapped.
17. Thinking of disappearing or running away.
18. Not being able to laugh or feel joy.
19. Withdrawing from activities and the lives of others.
20. Feeling hopeless most of the time.
21. Loss of compassion.
22. Resenting the care recipient and/or the situation.
23. Neglecting or mistreating the care recipient.
24. Frequently feeling totally alone even though friends and family are present.
25. Wishing simply “to have the whole thing over with.” Playing the “if only” games; saying over and over “If only this would happen” or “If only this hadn’t happened.”



News and Notes

Heating Benefits

This year benefits were raised for those eligible for assistance with heating bills. Older adults can call the Office for the Aging to inquire about getting the **HEAP** benefit (maximum monthly income: \$1,963 for an individual; \$2,567 for 2-person household).



Access to Home

Another benefit available to low-to-moderate income persons with disabilities is the *Access to Home* program. It provides “assistance with the cost of adapting homes to meet the needs of those with disabilities to enable them to continue to live comfortably in their homes and avoid institutional care.” To discuss income guidelines and other program details, contact Sheen Housing at (585) 657-4114. For information on other home repair and weatherization programs available to seniors in Tompkins County, call the Office for the Aging, 274-5498.



Concerns about Driving

A popular handbook has recently been revised and reprinted, titled: *When You Are Concerned: A guide for families concerned about the safety of an older driver*. Copies are available at the Office for the Aging or online at www.aging.ny.gov/Caregiving/OlderDriver/DriverIntroduction.cfm



Rec. Therapy for Caregivers

Angela Andiorio, a certified therapeutic recreation specialist, has started a practice locally to assist family caregivers of older adults with dementia and other caregivers to increase their overall well-being through optimal leisure and recreation. You can call her at 607-216-7384 or view her website at <http://www.spaceandtimeconsulting.com>.

Recreation
Therapy

Tai Chi for Arthritis

Sun style Tai Chi will be offered for people with arthritis on Tuesdays, Jan. 13 through March 3 at the Finger Lakes Independence Center, 215 Fifth St., Ithaca. “It is characterized by agile steps. The forward and backward motion improves mobility...” For information, contact Marilyn Roberts Chase at 274-5488.



Free Occupational Therapy

The Ithaca Health Alliance has joined with Ithaca College to offer free OT services at the Ithaca Free Clinic.



Occupational therapy helps people with disabilities improve their abilities to live as independently as possible by teaching their daily life skills (e.g., training to use adaptive equipment, helping to cope with arthritis, ensuring elderly people are cared for properly.) Call the clinic (330-1254) to schedule an appointment on Tuesdays from 4-7pm.

Exercise Video

The National Institute on Aging has produced an exercise video designed especially for those age 50 and older. Simply titled “Exercise,” it demonstrates easy-to-follow safe and effective ways to keep physically fit and improve overall health. It features Margaret Richard, star of *Body Electric*, PBS' popular exercise show. The 48-minute video or DVD costs \$7.00. For a copy, send a check for that amount to N.I.A., P.O. Box 8057, Gaithersburg, MD 20898. For more information, call 1-800-222-2225. It can also be ordered online at www.nia.nih.gov/HealthInformation/Publications/ExerciseGuide/video.htm.



Counseling and Support Groups Make a Difference

A study published in the journal *Neurology* found that spousal caregivers who participate in a program of individual and family counseling along with support group participation and the availability of telephone hotline resulted in a 28% reduction in the rate of nursing home placement. This translated into a predicted delay in nursing home placement of an average of 557 days when compared to the control group. In addition, those who participated in the program had better satisfaction and lower levels of depression.

A support group provides a safe environment to discuss fears and emotions. Group involvement has been shown also to ease a sense of isolation and reduce stress. Although you can confide in a trusted friend, especially one who has been a family caregiver, it may also be beneficial to draw on the experience of different people as not everyone reacts to situations in the same way.

Relationships with other attendees at a support group meeting are not as complicated as our relationships with relatives may be. We don't expect other participants in the groups to fix our problems. We just want to listen and be listened to.



We may learn more about the disability or illness of our care receiver as we listen to others. We may get some ideas of caregiving strategies at the meeting. We also might learn about community services and programs that have helped others. Some attend for a while to learn from others and then stop coming until their caregiving situation becomes more complicated or stressful. Others keep attending as they benefit greatly from the sense of reduced isolation that the support group connections bring to them.

Most caregiver support groups are led by a facilitator who encourages conversation and may provide information and some guidance.

In Tompkins County:

1. The *Caring for Aging Parents* group is an evening group that meets on the third Wednesday of the month.
2. There are two *Alzheimer's Support Groups*—one an afternoon meeting and the other that meets in the early evening.

There is also a Parkinson's Support Group that meets monthly in Tompkins County. Details for all of these groups are found on page 2 of this newsletter.

On Campus:

Cornell and Ithaca College each have *support groups* for employees who are family caregivers that meet on campus during the work day. For details, at Cornell, contact Eileen Whang at Day Hall (255-3976); at IC, contact Pam Mayberry (274-1607)

In Cortland:

Some who live in the northeast part of Tompkins County may find **support groups in Cortland** more convenient. They are welcome to attend the Family Caregivers Support group that meets generally on the 4th Thursday of the month at 7:00 PM (in December, it is moved up a week to the 18th) at Access to Independence, 26 N. Main St. Call the Cortland Caregivers' Resource Center for further information (753-5060).

There is also an *Alzheimer's Support Group* that meets at Walden Place, 839 Bennie Road, Cortland on the 3rd Wednesday of each month, 1:00 PM. (Call 756-8101 for more information).

Tips for Caregivers of People with Alzheimer's Disease

(From the National Institute on Aging)

Sleep Problems

For the exhausted caregiver, sleep can't come too soon. For many people with AD, however, the approach of nighttime may be a difficult time. Many people with AD become restless, agitated, and irritable around dinnertime, often referred to as "sundowning" syndrome. Getting the person to go to bed and stay there may require some advance planning.



- Encourage exercise during the day and limit daytime napping, but make sure that the person gets adequate rest during the day because fatigue can increase the likelihood of late afternoon restlessness.
- Try to schedule more physically demanding activities earlier in the day. For example, bathing could be earlier in the morning, or large family meals could be at midday.
- Set a quiet, peaceful tone in the evening to encourage sleep. Keep the lights dim, eliminate loud noises, even play soothing music if the person seems to enjoy it.
- Try to keep bedtime at a similar time each evening. Developing a bedtime routine may help.
- Restrict access to caffeine late in the day.
- Use night lights in the bedroom, hall, and bathroom if the darkness is frightening or disorienting.

Coping with Holidays

Holidays are bittersweet for many AD caregivers. The happy memories of the past contrast with the difficulties of the present, and extra demands on time and energy can seem overwhelming. Finding a balance between rest and activity can help.

- Keep or adapt family traditions that are important to you. Include the person with AD as much as possible.
- Recognize that things will be different, and have realistic expectations about what you can do.
- Encourage friends and family to visit. Limit the number of visitors at one time, and try to schedule visits during the time of day when the person is at his or her best.
- Avoid crowds, changes in routine, and strange surroundings that may cause confusion or agitation.
- Do your best to enjoy yourself. Try to find time for the holiday things you like to do, even if it means asking a friend or family member to spend time with the person while you are out.

At larger gatherings such as weddings or family reunions, try to have a space available where the person can rest, be by themselves, or spend some time with a smaller number of people, if needed

Videocaregiving Site Launched

Terra Nova films has launched a website that is dedicated to "streaming" visual educational materials to family caregivers. In the videos you hear real people in real situations so you hear first hand from caregivers and people with Alzheimer's disease. They discuss such things as "the feelings of those who live with the disease," "emotions of the caregiver: daughter and mother..." "simplifying tasks for the person with Alzheimer's," and "the nursing home discussion." You can check it out at www.videocaregiving.org



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 St., Ithaca. Open weekdays, 8:30 AM - 4:30 PM.

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Marilyn Roberts Chase, RN, Powerful Tools Coordinator

Telephone: (607) 274-5488

E-mail: mroberts@tompkins-co.org



Website of Interest to Family Caregivers:

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

(Click on "Gateway to Senior Seniors" at the top of the home page to access our resource guides and back issues of this newsletter.)

Tompkins County Long Term Care Services: www.tompkins-co.org/dss/ltc

Family Caregiver Coalition (California-based): www.caregiver.org

H.E.L.P (legal and financial issues, California-based): <http://www.help4srs.org>

National Alzheimer's Association: www.alz.org

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