



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 2008

Vol. 20, Number 3

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Dear Reader,

How quickly the summer flies by. I hope it has provided you with some change of pace. If not, you may need to take a hard look at the article on “Respite Options” on page six. Please don’t let expense be your excuse for not planning a needed break. Give us a call here at the Office for the Aging to take advantage of funds available to help family caregivers take short-term breaks or get other needed help to lessen the strain.

The fall also has us resuming our schedule of workshops and classes for family caregivers. Some of you have already signed up for the Powerful Tools classes beginning at the end of September. Give us a call to get more information about these classes or the other educational programs listed on pages three and four.

After two years of not having a Memory Walk here in Tompkins County, we will again have one to help support the work of the Alzheimer’s Association in advancing research into effective treatments as well as supporting families who are already trying to cope with the disease.



Finally, the staff of the Caregivers’ Resource Center here at the Tompkins County Office for the Aging are available as usual to consult with you about family caregiving – both your present challenges as well as future planning. Give us a call when you need us.

Dave Stoyell, Coordinator
Caregivers’ Resource Center

Fall 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: (Sept.- no meeting, Oct. 15, Nov. 19) 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: (Sept. 23, Oct. 28, Nov. 25)
- 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: (Sept. 17, Oct. 15, Nov. 19)
- 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 (Oct. 1, Nov. 5, Dec.3). 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.

Fall Presentations for Family Caregivers at the Cooperative Extension Education Center 615 Willow Ave., Ithaca

(These three free workshops are sponsored by the Caregivers' Resource Center of the Tompkins County Office for the Aging. **Pre-registration is encouraged**, but not required. To register or for other information on supports for people caring for aging relatives, contact the Office for the Aging (phone: 274-5492 or e-mail: dstoyell@tompkins-co.org).

Caregiving from a Distance **Wednesday, October 15, Noon-1:30 PM**

Trudy Cedar, RN, a local geriatric care manager, will address concerns of those who live a short distance or many miles away from a relative with long term care needs. Issues to be addressed include assessment of needs, communications issues, coordinating care, and other issues of concern to those in attendance. Bring your brown bag lunch, if you wish. Beverages provided.



Alzheimer's: Managing Challenging Behaviors **Friday, November 7, Noon-1:30 PM**

Michael Massurin, Director of Programs and Services for the Alzheimer's Association of Central New York will discuss what causes dementia-related behaviors like suspicion, repetition, sundowning, agitation and aggression and how to respond to these behaviors. Bring your brown bag lunch if you wish. Beverages provided.



Lee Silverman Voice Treatment **Wednesday, September 17, 2:00-3:30 PM**

Phyllis Mazurski, a speech-language pathologist (therapist) at the Cayuga Medical Center, will describe how Lee Silverman Voice Treatment (LSVT) can help restore vocal communication for people with Parkinson's Disease. Recently, LSVT has been successfully applied to individuals with multiple sclerosis, stroke, ataxic dysarthria, aging voice, and vocal fold paralysis.

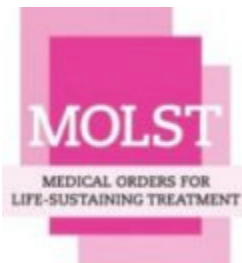


Medical Orders for Life-Sustaining Treatment (MOLST)

Monday, 9/29, 3:30PM- 5:00PM,

Presenter: Bill Hawley

This free presentation will introduce participants to the MOLST program. Utilization of the MOLST form takes Advance Care Planning a step beyond the Health Care Proxy and Living Will. The Medical Orders for Life-Sustaining Treatment (MOLST) is a program designed to improve the quality of care people receive at the end of life by translating patient/resident goals and preferences into medical orders. MOLST is based on communication between the patient/resident, Health Care Agent or other designated decision-maker and health care professionals with the goal of ensuring informed medical decision-making.



Quality Time: Reconnecting with Your Loved One

at Lifelong, 119 W. Court St., Ithaca

Tuesdays, 9/2-9/30, 6:30PM- 8:00PM

Angela Andiorio (5 sessions)

This leisure education program is specifically designed for caregivers (family member or friend) of loved ones with dementia. Leisure education is a way to help you learn how leisure activities can improve your well-being and quality of time with your loved one. Goals of the program are to help caregivers decrease stress, increase enjoyment of life, increase the connection to their loved one, and increase the quality of time spent together. Call 273-1511 for registration details.



Long Term Care Insurance: Do You Need It?

Free presentations by David Stoyell, Aging Services Specialist at the Office for the Aging. Call the Office for the Aging, 274-5492 or Lifelong, 273-1511, to register for any of the following:



At Lifelong, 119 W. Court St., Ithaca

- September 24: 8:00 – 9:00 AM, includes free continental breakfast starting at 7:45 am
- November 8: 10:00 --11:30 AM.
- December 5: 8:00 -- 9:00 AM, includes free continental breakfast starting at 7:45 AM.

At Cooperative Extension, 615 Willow Ave., Ithaca

- September 26: Noon– 1:30 PM

At the Southworth Library in Dryden.

- October 8: 6:30 – 8:00 PM

At the Brooktondale Community Center

- October 23: 7:00 – 8:15 PM

Gerontology Institute Workshops

The Ithaca College Gerontology Institute Fall Workshop Series will be held at Longview on Tuesday afternoons from 2:00-4:30 p.m. The registration fee is \$20 per workshop, or \$70 if you attend all four. For people over 60 years of age and retired, the cost is \$12 per workshop. Call 274-1967 for more information/registration or email aging@ithaca.edu.

October 7 - Overview of Chiropractic Care in Older Adults

Paul Dougherty, D.C.
New York Chiropractic College

October 14 - Project Home

Rhoda Meador, M.S. and Amanda Torre-Norton
Cornell Institute for Translational Research in Aging

October 21 - Care Transitions

Diane Nanno, RN, BSN
Transition Coach, Crouse Hospital, Syracuse

October 28 - Complementary Medicine and Geriatric Care

Michael Eisman, M.D.

Feeling Stretched?

Let's Face It...

Caring for someone with a chronic illness such as dementia, heart disease, Parkinson's disease or stroke can be stressful physically, emotionally and financially.



Balance Your Life

POWERFUL
TOOLS
for Caregivers

Do You Help an Older Relative or Friend?

You May Benefit From:

Powerful Tools for Caregivers Classes

Powerful Tools for Caregivers is a six-week, educational program designed to provide you with the tools you need to take care of yourself while providing care for another.

You will learn to:

- Reduce stress
- Improve self-confidence
- Better communicate your feelings
- Balance your life
- Increase your ability to make tough decisions
- Locate helpful resources

The program consists of six, 2 ½ hour class sessions held weekly and is offered free of charge to Caregivers.
Not intended for Professional Caregivers

Pre-registration is required.

Call Tompkins County Office for the Aging 274-5488, to register or to inquire about the program.

September 23 - October 28 , Tuesdays 9:00 - 11:30 AM,
Kendal at Ithaca, 2230 N Triphammer Road, Ithaca

September 23 - October 28, Tuesdays 6:00 - 8:30 PM
Lifelong, 119 W Court Street, Ithaca

October 2 - November 6, Thursdays 2:00 - 4:30 PM
Cayuga Medical Center, 101 Dates Drive, Ithaca

Powerful Tools for Caregivers is Supported by a grant from the Community Health Foundation of Western and Central New York and co-sponsored by Tompkins County Office for the Aging, Lifelong, Cayuga Medical Center, Hospicare & Palliative Care of Tompkins County, and the Department of Social Services, Long Term Care.

Respite Options

Respice means taking a break from caregiving. It may be so that you can attend to other obligations, attend a distant family gathering, recuperate from your own surgery, or other things that come up that demand your attention. However, respite also can mean taking a break from something stressful so that you can “recharge your batteries,” to “retreat” and do some things you have found restorative to your spirit in the past, including relaxation, reconnecting to friends, hiking along a mountain stream, etc.

ASSESSMENT

Before selecting a respite option, some may benefit from having an assessment done to determine what care options are most appropriate in your situation. Contact **Tompkins Care Connection (274-5222)** to arrange for an in-home assessment at no charge.

IN-HOME RESPITE

Substitute care can come from a variety of sources including other family, friends, and paid aide service. Respite can be provided for brief periods (a few hours) or for long periods of several days or a week or two. When there aren't enough capable informal (unpaid) substitute caregivers, arrangements can be made with a licensed home care agency to provide substitute care while you are away. Some may hire aides privately, but then it is important that a trusted person be able to provide the care coordination normally provided by the nurse supervisor of the home care agency.

Family and Children's Service (277-8081), provides grant-funded home health aides once a week, usually in the afternoon, to give stressed caregivers a break. There is no charge for this service, although contributions are accepted.

The Office for the Aging's Project CARE program (274-5491) may also be able to provide weekly respite service provided by volunteers or

through a licensed home care agency when hands-on personal care may be needed.

RESPITE AWAY FROM HOME

If substitute care in the home, or in the home of a relative, cannot be arranged, a short-term stay in a residential care facility may be possible. In Tompkins County, these include:

Adult Homes (Longview, Clare Bridge, Bridges at Cornell Heights)

Family-type homes (Deer Haven, Old Hundred, Evergreen House)

Residences with Home Care Agency Service (Sterling House)

and area nursing homes.

Short-term stays in any of these residences depend upon the availability of room at the time needed. Again, an assessment may be needed by **Tompkins Care Connection** to determine what type of facility is appropriate.

IF YOU CAN'T AFFORD A GETAWAY



If you are having trouble affording some help needed to relieve caregiver stress, call the Caregivers' Resource Center or Project CARE programs at the Office for the Aging. The Office for the Aging has a fund from which it can make small grants to help caregivers get away for a few days or pay for other needed services that would make life a little easier for the caregiver.

ADULT DAY PROGRAMS

Finally, don't forget the Adult Day Program at Longview (375-6320) which operates Tuesday-Thursday, 9:00-3:00PM. It provides a break from caregiving and a chance for your loved one to get out and socialize. This coming year, we can look forward to Lakeside Nursing Home transitioning to an operation that will include a medical Adult Day Program and an assisted living residence in addition to providing skilled nursing care.

E-mailing the Doctor

According to Barry Jacobs, PsyD (July/August 2008 issue of *Caring Today*), “too many caregiver-physician relationships are weak alliances at best, and adversarial at worst. You can change this by deciding to actively support the doctor’s efforts.”

By making careful records of the effects of various treatments and a log of blood pressure readings, blood sugar readings, temperature, sleep patterns, etc., you can provide valuable information to the doctor.



Some physicians now use e-mail to communicate with patients and family members, although others are still not comfortable doing so. Ask about the physician’s preference. However you communicate, be organized so you can convey information and concerns in a concise way at the beginning of the visit to the doctor.

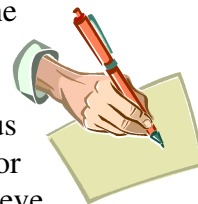
“If your physician accepts e-mails,” Dr. Jacobs writes, “at least two business days prior to the visit, send a detailed note identifying both your information and your questions.” Alternatively you might present a typed list of concerns and questions at the start of the appointment. This will enable the doctor to structure the appointment in a way that makes efficient use of the time allotted for the visit while still addressing your concerns.

If the doctor does a great job meeting your expectations, a word of praise and thanks goes a long way in helping a doctor persevere in offering the best care possible to patients. A thank-you note is even better.

To avoid patient-privacy concerns being an obstacle to an effective physician-caregiver alliance, be sure you have your loved one fill out permission forms that allow the physician to communicate with you. Also, be sure your loved one has assigned you as her health care proxy in case some time she is unable to fill out such permission forms.

Writing as a Caregiving Aid

Whether you are new to caregiving or have been at it for some time, whether the relationship is loving or antagonistic, writing about the different aspects of your caregiving experience can be therapeutic. Caregivers deal with a tremendous amount of stress. Expressive or therapeutic writing can help relieve stress and often leads to resolution of nagging problems. Writing is an inexpensive way for you to improve their circumstances and your health.



In addition to helping you free up your emotions, writing about caregiving can have medical benefits. Data show that when people write their deep thoughts and feelings about traumatic events, their heart rates slow, their bodies are better able to fight infection, and people feel a general sense of well-being. For more information, check out www.writingtoheal.com.

Reprinted from Broome County’s Caregiver Corner.

Humor Helps



The following were found in a list of “stupid questions”:

Can someone be scared half to death twice?

What do you say if God sneezes?

What happens to you if you pass a sign that says “Do not pass”?

Is a band-leader who works part-time called a semi-conductor?

Can you buy an entire chess set at a pawn shop?

Before drawing boards were invented, what did people “go back to?”

Holding a Family Meeting

“Having a family meeting is like having a bowling alley installed in your brain.” – Martin Mull

Mather LifeWays, in its *Care with Confidence* Newsletter, makes several suggestions you may want to consider before holding a family meeting to discuss family caregiving concerns.

They recommend asking everyone two questions before the meeting

What are your primary concerns now?

What are you willing to do?

In considering who to invite, it is best to invite everyone who has a stake in the outcome of the meeting and anyone who can offer a solution. Some may need to attend via a conference call. A person with dementia may not be able to make clear decisions, but may be aware of what they need and state preferences.



Consider having someone other than the primary caregiver or care receiver act as a facilitator, an important role to keep things on track and resolve conflicts. Sometimes a professional social worker, clergy person or case manager can be invited to lead the meeting.

Some suggested ground rules that might be agreed to at the beginning of the meeting:

- **Focus** only on your agreed-upon agenda
- Each of you will have a chance to **express your feelings** and preferences, but there will be no “button pushing.” The watchword is cooperation.
- **Brainstorm solutions** and voice all possible solutions without judging any of them at first. Later, choose which ones to try as your plan of action.

- Everyone can play a role in resolving concerns, but you also need **to be honest about your limitations**. Don’t volunteer to cook dinner for your loved one every night if that isn’t something you can do realistically.

Steps in Problem-solving

- Clearly identify problems and concerns.
(These were identified prior to the meeting, but need to be summarized at the meeting.)
- Gather information
(Present information that helps family members understand as much as possible about the disease and its challenges.)
- Generate options.
- Evaluate options.
(It will be helpful if some have done some research prior to the meeting to explore what options/strategies others have tried as well as community-based resources that might be available.)
- Create a plan.
(This may involve compromise if no “ideal solutions” are apparent to everyone. Might involve agreeing to try out something for a limited period of time. If it is complicated, you may want to write out a step-by-step plan or schedule each person’s responsibilities as well.)
- Try it out.
- Reassess and make adjustments as needed.

By honoring the feelings of each person, with a certain amount of patience and perseverance, workable solutions can be found. Addressing painful challenges together can lead to a more close-knit family.

(Source Material: “Holding a Family Meeting,” *Care with Confidence* newsletter, Issue #12 www.matherlifeways.com/re_caringnewsletter.asp.)

Alzheimer's Page

Musical Notes

“...As a therapeutic musician at long-term care facilities, I have witnessed how musical activities can bring renewed energy, stimulation and joy to those with dementia, as well as their caregivers. Here is my formula for a positive musical experience in a group or one-on-one.”



1. Prepare by finding appropriate music, in your own collection, at a local music store, at the public library, or by searching the Internet.
2. Select music the listener enjoys, such as tunes from a favorite time period, Broadway shows, or superstars like Judy Garland and Nat King Cole. For baby boomers, legendary groups like The Beatles or Simon and Garfunkel might work well.
3. Create your own sing-along by printing out lyrics from the Internet or a songbook in an enlarged typeface for easier reading. If you play an instrument to accompany the sing-along, do so at a slower pace and in a lower key.
4. Watch musical sing-along DVD's, some of which are especially designed for individuals with Alzheimer's Disease.
5. Play music during the holidays, since it can be a link to happier days and a tonic to loneliness.
6. Create a soothing atmosphere by playing classical music such as Mozart or Chopin or tune the radio to a classical music station.
7. Take some breaks. Listening to any kind of music for longer than one hour at a time can agitate some people with dementia. A 20-minute rest between sessions can help.

8. Supplement listening to music with a discussion about the performers. This might foster communication and reminiscing.
9. Add singing and humming to your daily activities and encourage your loved one to join in.

(By Barbara Jacobs. Reprinted with permission from the Summer 2008 issue of care Advantage. Ms. Jacobs has developed a DVD series of sing-alongs designed for seniors and those with dementia. For details, call 415.893-9929 or www.FrontRowSeatVideos.com.

Memory Walk

Clare Bridge and Sterling House of Ithaca are hosting a Memory Walk fundraising event for the Alzheimer's Association:

Saturday, September 13

Registration: 10:00 AM

Warm-up: 10:45 AM (led by an instructor from an area health club)

Walk: 11:00 AM

Location: Brookdale Senior Living Campus (formerly Alterra), 101 Bundy Rd., off Rt. 96 across from Candlewyck Apts.)

Approximately six laps around the property is one mile. The terrain is paved and there will be water stations for your comfort. After the walk, there will be a live band, snacks and good company. You do not have to walk to participate. Support the Alzheimer's Association and help beat this disease.



For information on walking, entering a team or making a donation, contact Amy Rebera at **607-351-7857**.

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.

David Stoyell, CRC Coordinator and Newsletter Editor

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E-mail: dstoyell@tompkins-co.org

Katrina Schickel, Project CARE Coordinator

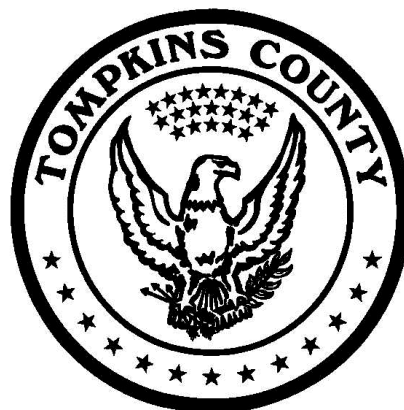
Telephone: (607) 274-5491

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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 Services" 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

National Alzheimer's Association: www.alz.org

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This newsletter is made possible in part by a grant from the NYS Office for the Aging.