



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 2014

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In this issue:

- ⇒ **Fall Caregiver Workshops**
- ⇒ **Professional Care Coordinators**
- ⇒ **How Heavy Is a Glass of Water?**
- ⇒ **Managed Long Term Care**
- ⇒ **Legal Help for Older Adults**
- ⇒ **Notes for Dementia Caregivers**

Register for Fall Programs Sponsored by the Caregivers' Resource Center

Starting later in September, we will again be offering our *Powerful Tools for Caregivers classes*. As this newsletter went to print, there were two seats open, so please call to register ASAP if you are interested. Also, please mark you calendars for these fall workshops for family caregivers, which are described in more detail on p. 3. Because of limited space, we do need you to call ahead to register to attend:

Upcoming First Thursday Speaker Meetings

Tompkins County Office for the Aging Conference Room
214 W. Martin Luther King, Jr/State Street

October 2, 6:30-8:00 PM: "*Exploring the Aging Experience*"
Speaker: Elizabeth Bergman

November 6, 6:30-8:00 PM: "*Common Struggles for Caregivers*"
Speaker: Ann Dolan

December 4, 1:00 – 4:00 PM "*Living with Alzheimer's- Middle Stage Caregiving*"
Speaker: Carol Ackley



Please note that the Alzheimer's Support Group continues to meet at the Office for the Aging on the 4th Tuesday of every month from 1:00-2:30 PM and is open to anyone caring for a loved one with any type of memory impairment/dementia. A caregiver support group open to those caring for family/friends with any condition is offered by Family and Children's Service on the 3rd Tuesday of each month. See page 2 and page 6 for more information on area support groups.

Local Caregiver Support Services

full day (\$38) and half-day (\$19) include lunch and snacks.

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging

David Stoyell (274-5492)

Katrina Schickel (274-5491)

The Caregivers' Resource Center & Alzheimer's Support Unit offers family caregivers information, 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** offer 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 having difficulty paying for those services. Call Katrina to discuss your needs.

Caregiver Counseling

Family and Children's Service

Ann Dolan (273-7494)



A caregiver counselor will meet with family caregivers periodically in her office or at their home and help them work through complex caregiving issues or provide emotional support. No charge. Donations accepted.

Adult Day Program

Longview Adult Day Community

Tuesdays, Wednesdays, Thursdays,
9 AM- 3 PM

Pamela Nardi (375-6323)



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. Both

Support Groups



Caregiver Support Group

3rd Tuesday of each month

6:30 PM-8:00 PM

Family and Children's Service
127 W. Martin Luther King Jr./State St., Ithaca.

Facilitated by Ann Dolan, LCSW. Especially for caregivers of older adults. Call for information, 273-7494. Important: Please ring buzzer located next to the front door for entry.

Alzheimer's Support Group

4th Tuesday of each month, 1:00-2:30 PM

Office for the Aging
214 W. Martin Luther King Jr/State St., Ithaca

Facilitated by David Stoyell. Open to anyone caring for a relative or friend with significant memory impairment. Call 274-5492 for more information.

Other Alzheimer's Caregiver Groups

1st Wednesday of each month at 6:00 PM.

at Lifelong, 119 W. Court St.. Ithaca. For info., call the Alzheimer's Association at 330-1647.

Last Thursday of the month, 5:30 PM Dinner, 6:00-7:00 speaker at Clare Bridge, 101 Bundy Rd., Ithaca. RSVP each month you plan to attend- 351-7857.

3rd Wednesday of the Month, 12:30-1:30 PM

at Walden Place, Cortlandville. Call 756-8101. Companion care for your loved one available during the meeting.

Fall Workshop Opportunities for Caregivers

Workshops offered by the Caregivers' Resource Center:

The following workshops are offered free of charge in the conference room of the Tompkins County Office for the Aging, 214 W. Martin Luther King, Jr./State Street, Ithaca.

Pre-registration is encouraged as space is limited.

Call the Office for the Aging to register or for details (274-5492).

Exploring the Aging Experience **Thursday, October 2, 6:30- 8:00 PM** **Presented by Elizabeth Bergman, PhD**



This session will engage participants in a number of activities designed to educate and sensitize individuals to the physical, psychological, social, and other changes that are common as we age. We will discuss the ways in which these changes can impact quality of life and explore strategies to improve communication and assist in overcoming and coping with age-related changes.

Dr. Bergman is an associate professor of Gerontology at the Ithaca College Gerontology Institute and has considerable direct experience working with older adults and their caregivers as well as doing research on issues affecting family caregivers of older adults.

Common Struggles for Caregivers **Thursday, November 6, 6:30-8:00 PM** **Presented by Ann Dolan, LCSW**



Caring for a family member or other loved one presents multiple challenges. There are communication changes, family dynamics, emotional and behavioral changes, lack of personal time, along with the difficult feelings of grief and loss...to name just a few. During this workshop, we will discuss some of the problems most common to caregivers, and explore those most important to those in attendance.

Ann Dolan works as a therapist for older adults and caregivers at Family and Children's Service of Ithaca. She has extensive experience working with individuals with dementia and those with mental illness.

Living with Alzheimer's for Caregivers: Middle Stage **Thursday, December 4, 1:00-4:00 PM** **Presented by Carol Ackley**



This 3-hour workshop is designed to provide caregivers with the knowledge and tools needed to cope with a diagnosis of Alzheimer's or related dementia as the disease progresses through the middle stage.

- Part One: Symptoms of Middle Stage, Communication, Relationship Changes, Personal Care
- Part Two: Behavior Changes, Med. Management, Home Safety, Driving, Living Alone, Wandering
- Part Three: Day Services, In-Home Care Services, Senior Living Options, Caregiver Needs

Carol Ackley is the Associate Program Director of the Central New York Chapter of the Alzheimer's Association.

News and Notes

Elder Care Forum

You are welcome to join in a community health forum along with experts from this region to talk about Elder Care. “Financial advisers urge us to save for retirement, but a lot of other kinds of planning should be done as well (by individuals, communities and government).”



Dr. Karl Pillemer (gerontologist), Dr. Bill Thomas (Eden Alternative founder), and Martha Stettinius (author) will participate in the forum moderated by Catherine Lopez, of WRVO radio.

Monday, September 29 at 2:00-3:30 PM
Tompkins County Public Library

Borg-Warner Community Meeting Room

Free and open to the public. No registration required. For more information, visit: <http://wrvo.org/post/elder-care-community-health-forum>

Harvest Moon Dance

The Harvest Moon Dance is an annual intergenerational event sponsored by the AGES student organization (Aging and Gerontologic Education Society) at Ithaca College. This free event is on Friday, November 7 from 6:30-8:30 PM in Emerson Suites on the Ithaca College Campus. All local older adults and their family caregivers are invited to join Ithaca College students for a night of live music, dancing, refreshments and great conversation. No registration necessary. Questions? Call 274-1965.



Driver Evaluation

Eleanor Liebson, works for Cayuga Medical Center as an outpatient therapist (Brentwood Campus). She is now conducting clinical driver evaluations (with a doctor’s prescription) when there is a question of safety or when one’s physical or cognitive abilities have changed or declined. For more information on



the assessment, contact Ms. Liebson at 274-4159 or email eliebson@cayugamed.org.

Envisioning Your Retirement

The Lifelong Learning program has announced a



new workshop series called “Lifelong Transitions.” It is intended for pre-retired adults to assist them in developing a successful retirement plan. Attendance at the opening and closing sessions, “Envisioning a Successful Retirement,” on September 10 and October 27, is required for those who want to participate in the program.

A number of elective (optional) workshops will offered between the two required sessions including speakers on Financial planning/Wealth Management, Elderlaw, Aging Parents, Residential Care, Medicare Basics, Volunteering for Health and Community, Downsizing, and Powerful Tools for Caregivers.

For more information, visit the Lifelong website at www.tclifelong.org or call Lifelong at 273-1511.

Access to Home Program

The *Access to Home Program* of Better Housing for Tompkins County provides funding to income eligible homeowners with a disability or those living with a family member who has a disability. Home accessibility improvements include, but are not limited to: ramps, lifts, walk-in showers, and other bathroom and kitchen modifications. Call Better Housing for Tompkins County at 273-2187, ext. 201 to inquire.



How Heavy Is a Glass of Water?

A lecturer explaining stress management to an audience raised a glass of water and asked them how heavy it was. After a range of answers, the lecturer replied, “The absolute weight doesn’t matter. It depends on how long you try to hold it. If I hold it for a minute, that’s not a problem. If I hold it for an hour, I’ll have an ache in my arm. If I hold it for a day, you’ll have to call an ambulance...the longer I hold it, the heavier it becomes.”



He continued, “and that’s the way it is with stress management. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won’t be able to carry it. As with the glass of water, you have to put it down for a while and rest before holding it again...”

That applies to a lot of burdens, whether relating to work, family obligations or other commitments. But it is surely true for those carrying the weight of caring for an older adult.

Caregivers can make many excuses why it is impossible to take a break from caregiving (“not worth the effort to arrange it,” “no one can care for them as well as I do,” too costly). Jane Meier Hamilton writes: “Struggling with doubts and excuses like these, caregivers often forego time off, unaware that prolonged and intense caregiving takes a toll on physical and emotional health. It can lead to significant illnesses and caregiver depression, and to family, workplace and financial problems.” (*Aging in Action, Mathers Lifeways, June 18, 2014*)

If you’ve been carrying the weight of caregiving without breaks, consider the following:

1. Substitute care can come from a variety of sources: family, friends, neighbors, or volunteers from the community or faith-based organizations, as well as paid caregivers from agencies or privately hired individuals.
2. Respite can range from two or three hours weekly to a weekend getaway to a longer vacation. Some may be able to arrange for extended breaks of weeks or months by making arrangements with family members.
3. Help from family and friends or volunteers may come at no cost to the primary caregiver, while professional services will range in cost.
4. The choice of “substitute caregiver” may also depend also on your care receiver’s needs: ranging from companionship, housekeeping and errands, to personal care, to home health care (help with medications and specialized medical health care services). Whether volunteer or paid, you will want to assure that individual caregivers are qualified.
5. Finally, you will need to consider the pros and cons of the site where substitute care is provided: in home, at a relative’s home, or a short term stay at a residential care facility.

Connections with other family caregivers informally or through support groups may offer you leads on qualified and reliable caregivers. If your income is modest, you may qualify for some public assistance with home care costs. Those who have long term care insurance may find that their policies provide funds for respite care even if you are not yet at the point of using the policy for daily care.

Jane Meier Hamilton’s closing exhortation in her June 2014 *Aging in Action* column also bears repeating: “When you need a break from caregiving, arranging respite will be good for *both* you and your loved ones. As you do so much for others, remember to take good care of yourself.”

New Parkinson's Support Group

A new support group for people with Parkinson's or related movement disorders and their partners recently formed in Tompkins County. The group will meet on the second Monday of the month at 10:30 AM in Conference Room A at Kendal at Ithaca. If you or someone you know is interested in this group and/or plan to attend, call Evelyn Kalish, social worker, at 266-5354, or emailekalish@kai.kendal.org to RSVP or for questions.



Life Review/Reminiscence

Reminiscence about ways older adults have made significant contributions to society may be one of their most powerful developmental needs. Reminiscence work around generative stories can lead to late-life rebirth, revitalization, and can mitigate the fear of death. Hearing generative stories can help us recognize, respect, and sustain older adults' personal identities through a period when this is easily lost. Most importantly, it can be a tool for retaining older adults in connections with others. If you would like to learn ways to assist older adults in completing a life review of their generative contributions, register for this upcoming workshop sponsored by the Ithaca College Gerontology Institute (ICGI):

Life Review of Generative Contributions

Presenter: Myra Sabir, PhD

Monday, December 1

2:00-4:30 PM

**Country Inn and Suites,
110 Danby Rd. (Rt. 96B),
Ithaca.**



For more information and to register, go to www.ithaca.edu/agingworkshops or call the ICGI at 274-1607.

Stroke Recovery Group

The *Family and Friends Stroke Recovery Group* meets from 1:30-3:00 PM on the first Thursday of every month and is free to Tompkins County residents. The group is dedicated to empowering stroke survivors and their families to live full and complete lives. For information, call Dana Murray-Cooper at 342-2653 or email coop1663@aol.com.



Stroke Rehab Program

Ithaca College's Center for Life Skills runs a program intended for individuals who have been discharged from a formal rehabilitation program but deem it necessary to continue post rehabilitation services to improve the quality of their everyday life. The fall session is already running, but inquiries are welcome regarding next future sessions, which run for about three months and consist of approximately 10 hours of programming per week. Sessions take place at Longview, 1 Bella Vista Drive, in Ithaca.



The Center for Life Skills features a highly individualized goal-setting program provided by Ithaca College faculty and students from a variety of allied health disciplines including occupational therapy, physical therapy, therapeutic recreation, and speech-language pathology and audiology. These shared efforts focus on the integration of therapies to provide the best combination of services for each participant. For more information please contact program manager Catherine Gooch at (607) 375-6312 or cgooch@ithaca.edu.

Legal Help for Older Adults

A relatively new resource called LawHelpNY.org is now available to those who have Internet access.

Although the mission of LawNY is to provide information to those who cannot afford an attorney, on this website any older adults and their caregivers and advocates can get answers to a variety of legal questions. Also available are sample forms and information



about the courts, lawyers and social service organizations that provide services related to seniors. With a click of a button, you can read about topics like elder abuse, legal guardianship, power of attorney, avoiding foreclosure, landlord-tenant disputes, appealing denial of public benefits, and more. Sometimes these articles and sample forms might be enough to help you advocate for yourself or a loved one without the help of an attorney. Other times it may help clarify when it would be best for you to seek legal help or representation.

Other Common Legal Concerns that affect older adults include consumer fraud and scams, bankruptcy, age discrimination, grandparent custody and visitation, divorce, wills and estates, living wills and health care proxies, veterans' benefits, and Medicaid, Medicare or other health insurance benefits. These and other topics are listed conveniently on the home page of LawHelpNY.org. Choose the topic that concerns you and you will be directed to explanations of the issue, what people are entitled to, and sometimes the applications and forms needed to apply for a benefit or to appeal its denial. Sometimes the information provided includes a sample wording to help you draft your own letter to a company or agency to make your case.



Those who need help finding the information they need on the website, can click on **Live Help** to “chat” via instant messaging with someone who

can help them find what they need. Staff and volunteers from LawNY and its partner organizations are at the other end to direct you to the information you are seeking. LiveHelp is staffed Monday through Friday from 9 AM- 6 PM (EST).

Tompkins/Tioga Neighborhood Legal Services

(TTNLS), with an office in Ithaca at 215 North Cayuga St. (273-3667), is a division of LawNY. Its staff of attorneys and interns is assisted by paralegal staff and volunteers to provide free legal aid to people with certain civil legal problems. TTNLS assists low income people and older adults receive public assistance, food stamps, Medicaid and other public benefits including

Social Security Disability and SSI. They may be able to help prevent evictions, foreclosure, or other causes of homelessness. They sometimes assist people in creating



“power of attorney” documents. They also have helped in some instances with *pro bono* attorney referrals for help with other matters. However, they do not handle criminal issues, traffic violations, small claims, or most family court matters.

Attorney General’s Office: another helpful resource online for New Yorkers is the website of the New York State Attorney General found at www.ag.ny/gov.

Elderlaw Attorneys. Although most attorneys handle wills and setting up a “power of attorney,” for other issues, some seek the services of an attorney who specializes in estate planning or elderlaw issues. You can find a list of many Tompkins County professionals, including attorneys, who specialize in estate planning matters online at www.estateplanningcouncil.org or look in the ads in the yellow pages to see which attorneys or firms list elderlaw as areas of specialization.

Professional Care Coordinators

Who are professional Care Coordinators? They are either health professionals (such as nurses or social workers) or office staff who help schedule, arrange, and oversee services needed to maintain the health and well-being from someone with a serious or chronic illness. The role of the professional care coordinator can vary. Some may focus on medical care while others help with insurance, medication, or community services.



Professional care coordination may be provided by discharge planners, benefit managers, case managers, private geriatric care managers, or some other title. They may work in a:

- Health care facility such as a hospital, outpatient clinic, medical practice, VA hospital or clinic or primary care doctor's office.
- Health plan, private insurance company, managed long-term care plan (MLTC), or pharmacy benefit plan
- Medicaid program, or a program for people who get both Medicare and Medicaid
- Home care agency, county social services, or other community-based service.

Care Coordination is often cited as the key to better outcomes and improved quality of health care as well as a more person- and family-centered experience. But care coordination means different things to different people, and the role of family caregivers in coordinating care is often left out of the process. Two new *Next Step in Care* guides are designed to make it easier for family caregivers and professional care coordinators to work together more effectively. **A Family Caregiver's Guide to Care Coordination** provides basic information about who care coordinators are and how their roles

may differ depending on the setting. It gives practical advice and a list of questions that family caregivers can ask care coordinators, as well as tips for staying organized. The guide is free and available in four languages: English, Spanish, Chinese and Russian. (Note: **A Professional Care Coordinator's Guide to Partnering with Family Caregivers** is also available.)

(Reprinted from August 2014 newsletter Next Step in Care, published by the United Hospital Fund.). You can download either guide mentioned in the article from the Next Step in Care website found at www.nextstepincare.org or call the Office for the Aging, 274-5492 to be mailed a copy of the guide.)

Managed Long Term Care

One particular type of care coordination is provided by managed long-term care (MLTC). MLTC offers options to people who are chronically ill and need health and long term care services such as home care.

On December 1, 2014 anyone 21 or older who **has both Medicare and Medicaid** living in Tompkins County will be required to choose a MLTC plan if they will need home care or other long term care for more than 120 days.



The beneficiary will have a person-centered Plan of Care, which means that they will have an active role in planning their services. They will have a Care Manager who will get to know them and talk with them about their needs. The Care Manager will assist them and anyone else they want to involve (e.g., a family caregiver) in developing a Plan of Care that meets their needs. A letter will be sent by NY State Medicaid to those required to join a MLTC plan that outlines their choices.

Alzheimer's Notes

Corning Museum Tours

The Corning Museum of Glass and the Rockwell Museum are offering a free program for individuals with dementia and their caregivers.



"Meet Me at the Museum" tours are offered once a month from September through December and from February through May. These tours are being offered in conjunction with the Rochester/Finger Lakes Chapter of the Alzheimer's Association. To register, go online to www.alz.org/rochesterny and scroll down and click on the "Search Events" tab for the date of the next free tours.

Project Lifesaver

The Tompkins County Sheriff's Office is now enrolling people in Project Lifesaver. Project Lifesaver is designed for individuals living at home in the community who are at risk for wandering, including people with Alzheimer's or other forms of dementia. Participants are fitted with a personalized Project Lifesaver wristband that emits an automatic tracking signal every second, 24 hours a day. If a 911 call is made that the participant has gone missing, the signal can be tracked by trained personnel from the Tompkins County Sheriff's office using patrol cars and hand held equipment with radio frequency tracking ability.



There is a \$300 deposit for the equipment that is refunded at the time the equipment is returned and a \$10 fee for battery replacement every 60 days. However, no one will be turned away for inability to pay. The purpose of this program is to save lives and not to make a profit. Participation in Project Lifesaver can bring peace of mind to families, caregivers and communities.

If you want more information on Project Lifesaver or to enroll in Project Lifesaver, phone

the Tompkins County Sheriff's Office at 607-257-1345, ext. 455.

New in the Lending Library

Visit the Caregivers' Resource Center lending library in the Tompkins County Office for the Aging to peruse and borrow a wide variety of books and some DVD's on family caregiving topics, including a wide selection for caregivers of individuals with dementia. New additions:

I Will Never Forget: A daughter's story of her mother's arduous and humorous journey through dementia, by Elaine C. Pereira, 2014.



"...Just as her mother carried herself with grace and poise, so does Pereira here... With her detailed and well-written retelling of her mother's story, Pereira has delivered an insightful read for those taking similar journeys."

Second Wind: Navigating the Passage to A Slower, Deeper, and More Connect Life, by Dr. Bill Thomas, 2014.

"A beautifully crafted narrative on the forces that have shaped the baby boom generation...a road map for how this massive group can use their accumulated wisdom and elderhood as a force for cultural renewal, connection and deep healing."

The Caregivers: A Support Group's Stories of Slow Loss, Courage and Love, by Nell Lake, 2014

"A chronicle of ordinary people who do extraordinary things. They are inspiring and so is she."

That time of year thou mayst in me behold
When yellow leaves, nor none, or few, do hang
Upon those boughs which shake against the cold.
Bare ruin'd choirs, where late
the sweet birds sang.



In me thou see'st the twilight
of such day
As after sunset fadeth in the west,
Which by and by black night doth take away,
Death's second self, that seals up all in rest.
In me thou see'st the glowing of such fire
That on the ashes of his youth doth lie,
As the death-bed whereon it must expire
Consumed with that which it was nourish'd by.
This thou perceiv'st,

which makes they love more strong,
To love that well thou must leave ere long.

- WILLIAM SHAKESPEARE, SONNET 73

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, 214 W. Martin Luther King, Jr./State Street, Ithaca. Open weekdays, 8:30 AM - 4:30 PM.

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E-mail: kschickel@tompkins-co.org



Websites of Interest to Family Caregivers:

Tompkins County Office for the Aging: www.tompkinscountyny.gov/cofa

**Click on "Local Resources for Older Adults" to access our Tompkins County resource guides.*

**Click on "Newsletters" to view electronic editions of this newsletter for the past year.*

Family Caregiver Alliance: www.caregiver.org

Caregiver Action Network: www.caregiveraction.org

Next Step in Care: www.nextstepincare.org

Alzheimer's Association: www.alz.org

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