



# *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,

Periodically, we ask our readers for contributions to help defray the cost of the production of this newsletter. Those who receive this newsletter by regular mail can use the enclosed return envelope if you are able to contribute. Those who receive the newsletter electronically are invited to send your contribution to:

Tompkins County Office for the Aging  
214 W. Martin Luther King Jr./State St., Ithaca, NY 14850

Make checks out to “Office for the Aging” and put “Caregiver Newsletter” in the memo line. Of course, contributions are entirely voluntary. Also, we rely on subscribers to let us know when they no longer are involved with family caregiving and wish to be removed from this mailing list. Email or phone David Stoyell at the Office for the Aging to notify him (see contact information below).



Finally, mark your calendars for upcoming caregiver presentations of interest to you. There are more details on the following presentations on page 3 and 9. Please note that it is highly recommended that you call ahead to register for these workshops as space may be limited. Call our office at (274-5492) to register for any of them or email me at [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org).

March 3, 6:00-8:00 PM: *Safely Assisting with Transferring, Bathing & other Personal Care*

April 3, 6:30 -8:00 PM: *The ABC's of Well-Being: Strategies for Recovering Your Balance*

May 6, Noon-1:30 PM: *Alzheimer's Disease: The Basics*

# Local Caregiver Support Services

## 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 on family 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*

Monday thru Friday, 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. Fee: full day (\$45) or half-day (\$31 with lunch, \$22 without lunch).



## 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, before attending first time. 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**

Tompkins County 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 5:30 PM**

at Lifelong, 119 W. Court St.. Ithaca. For information, call Nicole Roustin, 279-5525.

**3<sup>rd</sup> 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.

### **Cancer Caregiver Group**

**2nd Tuesday of the month, 5:30-7:00 pm**

At the Cancer Resource Center of the Finger Lakes, 612 W. State St., Ithaca. For family, friends and caregivers of individuals with Cancer. For info, call 277-0960.

### **Parkinson's Spouses Group**

**Meets monthly at the Office for the Aging.**  
Call David Stoyell, 274-5492 for further

information.

# Upcoming Workshops for Family Caregivers

## Techniques for Safely Assisting a Loved One with Bathing, Transferring, and other Personal Care

Thursday, March 3, 6:00 PM- 8:00 PM

Center for Health Sciences, Room 203 at Ithaca College

After a discharge from the hospital or when a loved one gradually loses ability to do activities of daily living without assistance, family members may be called up to help. Training is often needed to offer assistance safely and efficiently.



A small group of Ithaca College Occupational Therapy graduate students will be hosting this 2 hour training session:

**Topics covered include: \*Transfers \*Bathing \*Dressing \*Fall Prevention**

Come and brush up on techniques, learn safety tips, watch demonstrations from students on safe transfers, and get hands-on experience with adaptive equipment. This workshop is sponsored by the Tompkins County Office for the Aging in cooperation with Ithaca College Department of Occupational Therapy.

**Registration** is required and space is limited. To register for this free training, or for more information call David Stoyell at the Office for the Aging, 274-5492 or email [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org). **Parking** is available in front of the Center of Health Science. Those who register will be given directions for parking and finding room 203.

## The ABC's of Well-Being: Strategies for Finding Your Calm Center and Recovering Your Balance

Thursday, April 7, 6:30 PM-8:00 PM

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

**Presented by Lisa Kendall, LCSW-R, CSW-G**

We've known for a long time that caring for an ill family member can create prolonged or high levels of stress, creating greater risk for developing chronic illness. In this busy world, it's important to notice when we feel stressed, and to quickly shift our minds and bodies to a calmer state, minimizing the impact of work and family stressors and reducing our vulnerability to illness.



In this workshop we will explore seven super-quick and fun ways to tap into your internal calming system, enjoy greater peace of mind, and learn about free resources to support your well-being. Lisa is a social worker and clinical gerontologist who specializes in aging and Elder care, living with chronic illness, and trauma recovery.

The workshop is free, but **please register to attend** by calling the Office for the Aging, 274-5492 or email [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org).

## Senior Living Expo

Saturday, April 2, 2016, 1:00-3:00 PM  
Ramada Inn, 2310 N. Triphammer Rd., Ithaca

Sponsored by the Tompkins County Office for the Aging and the Ithaca College Gerontology Institute. You will have the opportunity to view displays and speak to representatives from senior housing operators as well as to organizations providing services to help older adults age in place. The following two workshops will also be offered at the Senior Living Expo. Pre-registration is not required.



**1:15 PM (and repeated at 2:15 PM):** **Workshop #1:** *In-Home Services for Older Adults*  
**Workshop #2:** *Paying for Long Term Care*

## Upcoming Workshops at Lifelong (119 W. Court Street, Ithaca)

The following are free, but registration is required (phone 607-273-1511).

March 1, Noon-1:30 PM: ***Driver Fitness: What is It? Do I have it?***  
***What are my choices if driving isn't an option?***

Jonathan Maddison, Way2Go Program Manager at Cooperative Extension, and Eleanor Liebson, Occupational Therapist at Cayuga Medical Center, will discuss how conditions associated with aging can affect driving, what you can do to drive safely for as long as possible, and best transportation alternatives to driving. We will cover the role of caregivers as well as driver fitness and community transportation.

Tuesday, March 15, 5:30 PM-7:00 PM: ***Caring for the Caregiver***

Caregiving is emotionally, socially and financially stressful, and caregivers can become ill if their own needs are not met. This workshop will give you insight and permission to take care of yourself. Presented by Susan Suben, President of Long Term Care Associates/Elder Care Planning.



Thursday, April 21, 5:30 PM-7:30 PM: ***Medicare Basics***

Sarah Jane Blake, Outreach Coordinator for the NY Statewide Senior Action Council, will present information for those new to Medicare. Topics included will be Medicare Parts A, B and D and EPIC. Medigap plans, and Medicare Savings plans for low income Medicare beneficiaries.

(Another workshop, titled "***Sharing Your Wishes***" will be offered on Monday, March 7, 10:00-11:00 AM.

It will cover four easy planning steps for designating a health care proxy and communicating wishes about what kind of medical care you may want in the future. This particular workshop is restricted to members of Lifelong. To learn more about this membership in Lifelong (for persons age 50 and older) or about any of these upcoming workshops, call Lifelong at 273-111.)

**ICGI Workshop:** Wednesday, April 20, 2:00-4:30 p.m.: ***Palliative Care: Research and Practice***

Staff from the IC Gerontology Institute and Hospicare will discuss palliative care, How it benefits people, barriers to obtaining palliative care and present the results of a community survey of attitudes regarding palliative care and present the latest research on palliative care. Workshop will be held at the Country Inn and Suites, 1100 Danby Road (Route 96B). Register for the workshop online at [ithaca.edu/agingworkshops](http://ithaca.edu/agingworkshops). Fee: \$25 or \$15 for retired individuals.





# Don't Believe Everything You Think

**A**t an IC Gerontology Institute workshop last fall, Eleanor Liebson, an occupational therapist at Cayuga Medical Center, discussed the importance of “watching what you think” if you are to maintain your emotional well-being while coping with losses (or being a care partner to someone suffering losses).

Sometimes our thinking gets us in trouble if we seek to change what cannot be changed. She reminded us that there are “five unavoidable givens” built into the very nature of things, over which we are powerless (quoting from *The Five Things We Cannot Change and the Happiness We Find by Embracing Them* by David Richo):

## Five Unavoidable Givens

1. Everything changes and ends.
2. Things do not always go according to plan.
3. Life is not always fair.
4. Pain is part of life.
5. People are not loving and loyal all the time.

Do you catch yourself thinking otherwise? Too often we behave as if somehow these givens are not applicable to us. “When we resist reality,” Richo writes, “life can become an endless series of disappointments, frustrations and sorrows. Once we accept and embrace these fundamental facts, we come to realize that they are exactly what we need to gain courage, compassion and wisdom.” The desire to do this is encapsulated in Reinhold Neibuhr’s serenity prayer: “God grant me the serenity to accept the things I can’t change the courage to change the things I can, and the wisdom to know the difference...”

Author James McCrae reminds us that “the average person thinks between 50,000-70,000 thoughts per day. Some are mundane: I need to buy milk; some are significant: I love you; and some are self-destructive: I’m not good enough.” You are not your thoughts. You don’t have to believe every thought they comes into your mind. But you do need to spend time observing your

thoughts if you are not going to be controlled by them. When we were young, we may have thought that “mental health exercises” were intended for a select group of people. Maybe those who have mental illnesses, or perhaps monks seeking a way of perfection. Nowadays, it is recognized that if we neglect paying attention to our thoughts and emotions, we do it at our own peril.

In quiet moments, or whenever you are struck by a thought, whether it is initially perceived as “a bad thought” or “good thought,” you don’t have to immediately identify with the thought. You can be an “impartial observer” who says “It’s interesting that I think that. I wonder why?” Then focus on the way you want to live. James McCrae writes further that “mental clutter can distract us from our personal missions. Because what you focus on for a sustained period of time becomes your reality, it is essential to decide the purpose you want to fulfill and direct your mental focus toward this narrative.” (from *Don't Believe Everything You Think: 5 Tips for A Happier Mind*, James McCrae)



## S.T.O.P. Exercise

A simple technique anyone can employ in times of stress is the **S.T.O.P.** exercise:

**S:** Stop what you are doing for a moment.

**T:** Take a breath. Concentrate on the flow of your breath in and out.

**O:** Observe your thoughts, feelings and physical state. Notice your thoughts and let them be or pass. Name your emotions. Notice your body, its posture. Are you hungry or thirsty? Do you have any aches or pains?

**P:** Proceed with something that will be helpful to you, whether that is finding a friend to talk to, eating a nutritious snack or meal or stretching to relieve body tension.

# CARE Act Enables Family Caregivers at Hospital Level

The Caregiver Advise, Record, and Enable (C.A.R.E.) Act was signed into law by Gov. Cuomo in October and becomes effective this Spring. It requires hospitals to provide caregiver training, before the discharge of a patient, including instructions and a demonstration on aftercare (such as changing bandages or administering medication).

The C.A.R.E. Act requires that hospitals allow patients to formally designate a caregiver upon admission to a hospital. The hospital is required to record the name, phone number and address of the caregiver in the patient's medical record and notify the caregiver of the patient's upcoming discharge at least 24 hours in advance.



The law was passed because if hospitals fail to provide direction and clear care instructions for family caregivers, patients may end up back in the hospital after being discharged to receive care at home.

## Hospital Discharge Planning

Hospital discharge planning is only required if someone is admitted to the hospital **as an inpatient**. A discharge planning evaluation tries to foresee the patient's medical and other care needs after their hospital stay. The hospital's main goal during the evaluation should be to return you to the place you left before the hospital stay (this may be home or another facility). If this isn't possible, the hospital should recommend other, more appropriate places for you.

Make sure the hospital staff members consider your range of needs following the hospitalization. If returning home following surgery, the discharge planning evaluation should see whether you can care for yourself, or will need assistance from family, friends, or other community caregivers. The staff should also see whether you will need medical equipment or changes to your

home to make it safe. If going back to a facility, the hospital must make sure the facility can still provide the care you will need. Review which post-discharge services will be covered by Medicare and how much they will cost. If covered by another type of insurance, such as Medicaid, check to see what is covered.

## Your Preferences

Tell the hospital discharge planner about your needs and preferences for care after your hospitalization. Your needs and preferences must be incorporated into your plan of care.

As mentioned above, the staff must educate and train you, your family, and/or designated caregiver, about your care needs. Be sure you (and/or your caregiver) understand these directions and have a list of instructions for your care and all medications you will need. Also, make sure you have obtained referrals to other providers as necessary such as home health agencies, skilled nursing facilities, hospice, physicians, medical equipment suppliers, emergency response systems, or other needed supportive services.



Keep in mind that Medicare now pays your primary care provider to manage your care right after your hospital discharge. The hospital should send this provider information about your medical condition. Be sure to follow up with your primary care provider and other providers involved in your care.

## Discharge Planning Checklist

If you anticipate a hospital stay for yourself or a loved one, you can download the "Your Discharge Planning Checklist: for Patients and their Caregivers" from Medicare at [www.medicare.gov/Publications/Pubs/pdf/11376.pdf](http://www.medicare.gov/Publications/Pubs/pdf/11376.pdf).

## Family Councils

A nursing home “Family Council” is a consumer group of relatives and friends of nursing home residents. The primary focus is to influence and improve the quality of life in the home. Most meet on a monthly basis in a room provided by the facility. It is self-run, but may invite a staff member and/or the ombudsman to attend. They also allow family members to give each other the support, guidance and information they need to enrich their loved ones lives.



Feelings of helplessness and isolation that families may experience when placing a person in a nursing home can be channeled into positive actions for change in the system. A successful council is involved with families, residents, staff, and management in a manner that is conducive to effective communication, cooperation and mutual respect. They work best when the focus is on finding solutions to problems or identifying needed improvements. They should not just be “gripe” sessions. An effective council allows members to meet without a staff person being present. Shared concerns should be submitted in writing to the administration, who must respond in a timely fashion.

Studies have shown that all residents, even those without families, receive better care in homes that have active councils. The nursing home also benefits. Many times administrators were not aware of common concerns that were raised at a council meeting that may, in many cases, be easily corrected. **A family council is not:**

- a volunteer group or auxiliary,
- a family night hosted by the nursing home,
- a resident council.

Families are encouraged to attend their family council. For assistance in organizing a council, contact the Ombudsman Coordinator. For nursing homes in Tompkins, Schuyler or Chemung County, call 607-274-5498.

## “Try-It” Room at FLIC

The Finger Lakes Independence Center (FLIC), located in downtown Ithaca, has what they call their “Try-it Room.” It is loaded with all kinds of assistive devices and gadgets to make life easier for people with mobility, vision, hearing or cognitive impairments. People are invited to stop by and try them out, or borrow them for a up to a month, to see if they might be useful before purchasing something similar. FLIC also assists folks in finding online, mail order or local stores that sell assistive devices. Some examples of the hundreds of items in the Try-it Room:

**TV Ears** - If you strain to hear words on TV, or family members complain that the TV is loud, TV Ears is the answer for you. TV Ears is a powerful, effective, and affordable solution recommended by Otolaryngologists, E.N.T.s, Audiologists and Hearing Instrument Specialists. TV Ears have voice enhancement technology, automatic commercial control, amplification, with volume, tone, and balance controls.

**Cutting board with pivot knife**- allows chopping of food with only one hand, bringing independence back to the kitchen for those in your care who love to cook. Safe and effective pivot holds knife and allows chopping at up to a 90° angle. The food-grade cutting board secures to the work surface with 4 suction cups that prevent it from sliding during use.

**Bed caddie**- is a bed mobility aid that enables people with general weakness or decreased back strength to pull themselves up to a sitting position in bed. This 3 tiered ladder system has cushioned grip handles and is made of durable nylon.

**Take Your Pills**- The "Take Your Pills" Talking Alarm Clock alerts users when it's time to take medication with a friendly female voice up to 4 times daily. Set up to 4 Daily Alarms to alert you when your medication is due. A repeating friendly reminder notifies you of the time, the date and which daily dose to take. ("Good morning! Please take your morning pills for the 20th.")



## News and Notes

### Inadvertent Lapse of LTC Insurance

The Center for Retirement Research at Boston College released a troubling study in 2015 which found that about 25% of long term care insurance policy holders who entered a nursing home had let their policy lapse during the preceding four years, resulting in loss of benefits they had supported with premiums earlier in their lives. The moral of the story: first of all, know whether or not your loved ones have purchased LTC insurance; secondly, if they have, be sure they keep up the payments, especially when physical or cognitive issues increase the chances they might neglect paying the bill and inadvertently lapse the policy they paid into for many years.



### Cancer Resource Guide

The Cancer Resource Center of the Finger Lakes recently updated its resource guide for cancer support services in Tompkins County. Although it's focused on cancer, many of the resources may be helpful for other conditions as well. View it at [www.crcfl.net/wp-content/uploads/2016/01/Cancer-Support-Services-Guide-2016.pdf](http://www.crcfl.net/wp-content/uploads/2016/01/Cancer-Support-Services-Guide-2016.pdf)



### Share Your Input about Housing

Your input is needed to help Tompkins County develop a Housing Needs Assessment to better understand housing needs and to project housing demand within Tompkins County through 2025. Whether you live in or commute into Tompkins County, please share your thoughts by taking the survey at <http://e-input.com/surveys/tompkins.htm> now through Monday, February 22, 2016.



### LGBT Aging Center

The National Resource Center on LGBT Aging has a number of online guides for LGBT caregiving, including resources for legal and financial planning, health care, retirement, caregiving tips, and more. Visit [www.lgbtagingcenter.org/caregiving](http://www.lgbtagingcenter.org/caregiving) to explore what is available.



### Caregiver College Video Series

The Family Caregiver Alliance (FCA) YouTube channel offers free chaptered videos in their Caregiver College Video Series. For an orientation to the video series and links to videos on the topics that follow, visit

[www.youtube.com/watch?v=xUjOarB8XUc](http://www.youtube.com/watch?v=xUjOarB8XUc) .

- Ch. 1 Transfer skills
- Ch. 2 Nutrition
- Ch. 3 Dental Care
- Ch. 4 Bathing and Dressing
- Ch. 5 Toileting and Incontinence
- Ch. 6 Behavior Issues
- Ch. 7 Self-care



### Bereavement Support Group

Meets on the first and third Wednesdays of the month, 5:30 to 7:00pm at The Nina K. Miller Hospicare Center, 172 East King Road, Ithaca. This group is for anyone 18 years of age or older grieving a loss, regardless of when the death occurred. If this is your first time coming to the group please contact Donna George at [dgeorge@hospicare.org](mailto:dgeorge@hospicare.org) or [607-272-0212](tel:607-272-0212). Otherwise there is no registration required.



# Alzheimer's Page

## Alzheimer's Disease: The Basics

**Presentation by Whitney Hadley,**  
Associate Program Director of the CNY  
Alzheimer's Association

**When:** Friday, May 6, Noon-1:30 PM

**Where:** Tompkins County Office for the Aging  
214 W. Martin Luther King Jr./State St.

This workshop discusses the difference between normal aging and dementia, how the brain works, defines dementia and goes through different stages of the disease. Also gives an overview of programs and services of the Alzheimer's Association and services offered by the Office for the Aging and other agencies in Tompkins County to support families impacted by Alzheimer's or related disorders causing dementia. To register, or for more information, call the Office for the Aging, 274-5492.



## Other Bulletins/Newsletters

1. **Monthly Email Bulletin-** The Tompkins County Office for the Aging sends out a monthly bulletin to family caregivers of individuals with dementia. It lists upcoming events and groups of interest to persons with dementia and/or their caregivers. It also usually includes an article of interest to family caregivers. Email David Stoyell at [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org) to be added to this mailing list.



2. **Perspectives** is a quarterly publication written for persons with dementia in the early stage. It is sent by mail (free of charge) by the Shiley-Marcos Alzheimer's Disease Research Center at the University of San Diego. Simply email Lisa Snyder at [lsnyder@ucsd.edu](mailto:lsnyder@ucsd.edu) to request an electronic subscription.

## Caregiving is Hard Work

*Liz is a 78 year old widow with dementia. Liz's daughter, Joanne cares for her. Although Joanne tells Liz not to cook, she always tries to anyway and leaves the stove on. After many such incidents, Joanne becomes furious and yells at Liz, threatening to put her in a nursing home.*

*Steve cares for his wife Martha who has dementia. Steve feels that each days is becoming more difficult for him as her condition gets worse. He is stressed and worried about letting out his frustration on his wife. Steve calls the Office for the Aging (or the Alzheimer's Association "helpline") to see if he can find a support group or counselor so that he can talk about his feelings.*

Caregiving can be overwhelming. It involves not only strenuous physical tasks, but also managing financial matters, organizing care, and so much more. Additionally, caring for someone with dementia can have particular challenges such as:



- Making sense of an unclear diagnosis
- Managing multiple medications
- Feeling pressure to be "on watch" 24/7
- Losing a partnership
- Lack of personal time or family support
- Managing sleep problems

If you are in this situation you may be feeling isolated, stressed, overwhelmed or all of the above. These feelings are perfectly normal! But when ignored, they can be harmful to both you and your loved one. As Steve did, in the second scenario above, make a call if you need help with:

- Figuring out how to take care of yourself
- Learning how to ask for help
- Learning to respond appropriately to difficult behaviors
- Identifying "stress triggers"

*(adapted and reprinted from brochure produced by the Keck School of Medicine of USC)*

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

Please call or visit us  
at the **Tompkins County Office for the Aging**  
214 W. Martin Luther King, Jr./State Street, Ithaca.  
(Open weekdays, 8:30 AM - 4:30 PM)

**David Stoyell, CRC Coordinator and Newsletter Editor**

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Telephone: (607) 274-5491

E-mail: [kschickel@tom-pkins-co.org](mailto:kschickel@tom-pkins-co.org)



## Websites of Interest to Family Caregivers:

**Tompkins County Office for the Aging:** [www.tompkinscountyny.gov/cofa](http://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](http://www.caregiver.org)

**CaringBridge:** [www.caringbridge.org](http://www.caringbridge.org)

**Caregiver Action Network:** [www.caregiveraction.org](http://www.caregiveraction.org)

**AARP Caregiver Resource Center:** [www.aarp.org/home-family/caregiving](http://www.aarp.org/home-family/caregiving)

**Next Step in Care:** [www.nextstepincare.org](http://www.nextstepincare.org)

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