



# *In Support of Caregivers*

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

Winter 2012-13

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## **Office for the Aging Plans Move to New Location**

In mid-January of 2013, the Tompkins County Office for the Aging will move to its new location in the Human Services Annex at 214 W. Martin Luther King Jr./State Street. Our phone numbers will remain the same. Look for the date of the move in the local media or call our office (274-5482) or visit our website before stopping by.

## **Project Lifesaver**

The Tompkins County Sheriff's Department will be implementing Project Lifesaver early in 2013. It is designed for individuals living at home in the community who are at risk of wandering; for example, those diagnosed with Alzheimer's disease, autism or Down Syndrome. Project Lifesaver may make a difference by assisting Law Enforcement with the timely recovery of a missing person.



Each participant enrolled in the program will be fitted with a personalized Project Lifesaver wristband, which is a one-ounce battery operated transmitter that emits an automatic tracking signal every second, 24 hours a day. The signal can be traced by trained personnel from the Sheriff Department using equipment with radio frequency tracking capability. Look for more details in the media or contact David Stoyell (274-5492 or [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org)) at the Office for the Aging if you would like to be notified when enrollment in the program begins.



## Winter Support Groups

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



### Bi-weekly General Caregiver Support Group Meeting

- Open to those caring for parents, spouses or other elderly relatives or friends.
- **1<sup>st</sup> & 3<sup>rd</sup> Thursday of each month: 6:30 PM (Jan. 3, 17 Feb. 7, 21 and March 7, 21)**
- Meets in the lounge at Lifelong, 119 W. Court St., Ithaca

### Alzheimer's Support Group

- Open to those caring for loved ones with Alzheimer's or other cognitive impairments
- **Meets the 4<sup>th</sup> Tuesday of each month (Jan. 22, Feb. 26, March 26)**
- 1:00 - 2:30 PM in the Office for the Aging in our new location:  
214 Martin Luther King/W.State Street, Ithaca

### Other Alzheimer's Groups

In addition to the daytime group (above), people caring for loved ones with Alzheimer's or related disorders may attend of these Alzheimer's Support Groups:

**1<sup>st</sup> Wednesday of each month** at Lifelong, 119 W. Court St., Ithaca at 6:00 PM. For information, call the Alzheimer's Association at 785-7852 ext. 119.

**3<sup>rd</sup> Wednesday of each month** at Walden Place, 839 Bennie Rd., Cortland at 12:30 PM. Call for Reservations at 756-8101.

## Local Caregiver Services

### Caregivers' Resource Center & Project CARE Services

*Tompkins County Office for the Aging*  
David Stoyell, Katrina Schickel (274-5482)

*The Caregivers' Resource Center & Alzheimer's* **Discover the Resource Center**

*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 having difficulty paying for those services. Call Katrina to discuss your needs.

### In-Home Counseling & Respite Service

#### *Family and Children's Service*

Robert Levine (273-7495)



A caregiver counselor will meet with family caregivers at their home, her office, or elsewhere and help them work through complex caregiving issues or for emotional support. This program also offers grant-funded respite aide service to give caregivers a needed break.

### 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. Includes lunch and snacks.

# Winter Workshop Opportunities for Caregivers

Please call the Office for the Aging (274-5492) or email [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org) to register for any of the following:

## *The Spiritual Needs of Family Caregivers*

**Thursday, February 7, 6:30-8:00 PM**

**at Lifelong, 119 W. Court St., Ithaca**

**Presented by Rev. Tim Dean**

**Chaplain, Cayuga Medical Center**

When people are in physical duress, their spirits also need attention to promote healing. This can be true as well for those challenged by the stress of family caregiving. The connection of mind, body, and spirit is well understood among those in the healing professions. At this meeting, Rev. Dean, Chaplain at Cayuga Medical Center, will discuss the spiritual needs of family caregivers as they cope with the illness and care needs of a loved one and grieve losses.



## *Medicare and Caregiving*

**Thursday, March 7, 6:30-8:00 PM**

**at Lifelong, 119 W. Court St., Ithaca**

**Presented by Sarah Jane Blake**

**NY StateWide Senior Action Council**

Sarah Jane Blake will discuss situations that can arise when caring for a loved one at home including the Medicare Home health benefit, Medicare coverage during hospitalizations, nursing home rehabilitation, Medicare appeals and other concerns attendees may have about how Medicare coverage works. She will make a “hospital tool kit” available to attendees that may be helpful in transitions to and from a hospital stay.



- See p. 9 for upcoming workshops for those caring for loved ones with Alzheimer's or related dementia.
- See p. 4 for next series of “Powerful Tools for Caregivers” classes.

## 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**

**Spring 2013**

## 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*.

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 - 90 minutes class sessions held weekly and is offered free of charge to caregivers.

**Not intended for professional caregivers**

**March 25— April 29 (Mondays)  
6:30 PM—8 PM  
at the Office for the Aging**

*At Our New Location:* **214 W. Martin Luther King Jr./State St.**

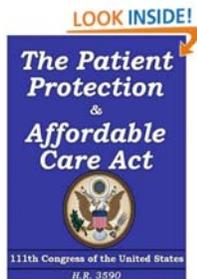
**Pre-registration is Required**

**To register or inquire about the program, Call:  
Tompkins County Office for the Aging, 274-5482**

Powerful Tools for Caregivers is offered by the Caregivers Resource Center of the Tompkins County Office for the Aging, with support from Cornell University, and NY Connects /Long Term Care Services Unit of the Tompkins County Department of Social Services

# How Health Care Reform May Impact Family Caregivers

The “Patient Protection and Affordable Care Act” has gradually been implemented in the past two years and more changes are to come. Now most preventative services are covered by Medicare with no co-pays. The Medicare D prescription benefit’s “donut hole” is gradually being closed. Medicare-covered benefits are not reduced or taken away by the law, nor does it reduce your ability to choose your own doctor.



Following are some of the changes that may assist family and friends in their caregiving role that will be implemented in the coming months and years:

**Quality Measure Development.** The law mandates the development of “quality measures” that assess the experience, quality and use of information provided to consumers, their caregivers and authorized representatives. Such information may inform decision making about treatment options, including the use of tools for shared decision making.

**Physician Compare Website.** Starting on January 1, 2013, the Physician Compare website must provide comparative information on the performance of physicians who participate in the Medicare program, including, to the extent possible, as assessment of consumer experience and consumer, caregiver, and family engagement in care. (Visit [www.healthcare.gov/compare](http://www.healthcare.gov/compare).)

**Center of Medicare and Medicaid Innovation.** This new Innovations Center may select models of care to be tested that put the individual, including family members and other informal caregivers, at the center of the care team. These models can also assist individuals in



making informed care choices by paying providers for using decision-supporting tools.

**Geriatric Education and Training.** Federally funded “geriatric education centers” working with community-based partners, will publicize and offer in their local service areas at least two courses annually to family caregivers and direct care workers. These courses should provide practical training in caring for frail older adults and individuals with disabilities. Another “demonstration project” will be directed toward training and certification programs to increase the number of home care aides.

**Protection for Recipients of Medicaid Home Care against Spousal Impoverishment.** Home-dwelling spouses of Medicaid assistance for nursing home care can currently retain a higher amount of income and assets than spouse of Medicaid recipients of regular Medicaid home care services. The new law requires states to temporarily extend these current “spousal impoverishment” provisions that apply to nursing home care to spouse of Medicaid beneficiaries receiving Home and Community-based Services (HCBS). This provision becomes effective in 2014 and applies for five years.



**Independent Payment Advisory Board.** This new board will have authority to recommend proposals to slow the growth of Medicare spending. A consumer advisory council will be established to advise the board. Not later than 2014, and annually thereafter, the 15-member board is required to produce a public report with information on health care costs, access to care, use of services, and quality of care for both Medicare and private payers. Each report must include an assessment of consumer and caregiver experience of care. The law anticipates that the Medicare Trust Fund will be extended as result of reducing waste, fraud and abuse and slowing cost growth in Medicare.

Stay tuned for more information as these and other changes are implemented.

# News and Notes

## TEPSAT Self-Assessment Tool

The State Office for the Aging and NY State Bar Association encourages you to go online to access the Elder Preparedness Self-Assessment Tool (TEPSAT). It is meant for anyone 50 or older and is intended to encourage people to be prepared for their elder years. It takes about 20 minutes and then an individualized report with suggestions is email to you. Visit [www.elderomn.com](http://www.elderomn.com).



[www.eldercare.gov](http://www.eldercare.gov) and scroll down the page to click on the link for the booklet.

## Consumer Advocacy

Those who are concerned about the lives and well-being of people receiving long-term care at home, in assisted living or in nursing homes, can join either/both of the following organizations if you want to advocate for legislation and public policy to improve long term care:

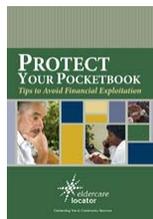


**Consumer Voice Action Network.** As a member of its nation Action Network, you will receive breaking news, action steps, newsletters and opportunities for you to take action regarding national and state policy developments in long-term care. Visit [www.theconsumervoic.org](http://www.theconsumervoic.org).

**Long Term Care Community Coalition (LTCCC) of New York.** Researches policies, laws and regulations affecting care for the elderly and disabled; and advocates for New York State and national policies to improve care. Visit [www.ltccc.org](http://www.ltccc.org).

## Protect Your Pocketbook

The consumer guide, *Protect Your Pocketbook: Tips to Avoid Financial Exploitation*, shares ways to avoid financial fraud, signs of exploitation and services to contact for assistance. It may be worthwhile reviewing before heading home for the holidays if you haven't seen older relatives in a while. Visit



## Way2Go Videos

Cooperative Extension's Way2Go program has on its website links to new transportation "how-to" videos produced in Tompkins County which introduce people to transportation options that may not be familiar to them. The following videos can be viewed from the comfort of your home on your computer at [www.Way2Go.org](http://www.Way2Go.org):



- Ithaca CarShare: How It Works
- Ridesharing: Why and How to Share More Rides
- Bus Basics
- Bus Basics for Wheelchair Users

All TCAT buses are now wheelchair accessible.

## Healthy & Active Living Workshop

Is a FREE 6 week program for people with an ongoing health condition (such as diabetes, Parkinson's, arthritis, congestive heart failure, fibromyalgia, etc.), although a family member, friend or caregiver is welcome to come with them. Sessions meet for 2 1/2 hours each week.



A six-week series will be held at Lifelong beginning April 15. Another series may be scheduled to begin at the end of January.

Call 273-8686 or send an email to [solmstead@hsctc.org](mailto:solmstead@hsctc.org) to find out more information about the workshop and register.

## Tips to Prevent Falls (if you or someone you care for has vision loss)

- Increase lighting in rooms so hazards can be identified, such as shoes on floor.
- Avoid glare (that can be caused by either artificial or natural lighting). Balance adding lighting to dark areas with hanging lightweight curtains or shades to reduce glare.
- Use contrasting colors (e.g., paint a contrasting color on the top edge of stops so you can see the stairs better. For example, use light color paint on dark wood. Fasten rugs to the floor to avoid tripping.
- Exercise regularly to improve balance and coordination.
- Have your vision checked at least yearly.
- Put in a night light.
- Position a lamp close to the bed where it is easy to reach.
- Keep emergency numbers in large print near each phone.
- Position furniture so the path is clear and so that you not likely to bump into corners of furniture at night.



Other easy steps to prevent falls are suggested in the “Tompkins County Falls Prevention Resource Guide” available from the Office for the Aging or on its website at [www.tompkins-co.org/cofa](http://www.tompkins-co.org/cofa).

## Emergency Preparedness

To take care of ourselves in an emergency is hard enough, but it is more challenging to be responsible for a loved one who needs us.

### For any emergency:

It is important to know the location of copies of important documents: power of attorney, health care proxy, health insurance cards, insurance policies, wills, bank account numbers, etc. Keep your cell phone charged and enough gas in the car to get safely to an emergency destination.

**GO** emergencies requires us to leave our homes to remain safe; **STAY** emergencies require us to stay in our homes to remain safe.

### For GO emergencies:

A small suitcase, backpack, or reusable handled shopping bag can be a great place to have the items you would need to care for your loved one: vital medications, medical equipment, medical supplies, personal grooming supplies, a list of important phone numbers such as family, doctors, and pharmacy; a list of medications taken by you and your loved one; change of clothes; pet supplies, if appropriate; cell phone; hearing aids and batteries



### For STAY emergencies:

Have the supplies to be self-sufficient for a few days in case you and your loved one become isolated (three day supplies of nonperishable food and drinking water per person and per pet); a battery powered or crank radio and flashlight; extra batteries; no less than a three day supply of critical medication and medical supplies, if required.

For more information on Emergency Preparedness in Tompkins County, visit: [www.tompkinsready.org](http://www.tompkinsready.org).

# I'm a Caregiver, but Feel Like a Nurse!

By Carol Levine

These days, family caregivers are routinely performing tasks that a registered nurse would do in a hospital: managing feeding tubes, changing bandages after surgery, giving injections, checking blood oxygen levels, and much more. If you're a caregiver who may be facing such tasks, here are five questions you need to ask yourself:

**1. Are you able and willing to do these tasks?** Often family caregivers say that they feel pressured to take on the task mostly because there is no one else to do it, or because insurance wouldn't pay for assistance. You may be able to find ways around these barriers, such as home care agency services or enlisting another family member. But, remember, to get help, you need to ask for it.



**2. Do the tasks make you uncomfortable?** Different people have different levels of tolerance for performing tasks that require invasive procedures, like wound care, or intimate care — such as managing incontinence for a parent. Don't let others — professionals or well-meaning friends or family — disparage your reactions. Your feelings are valid. Many health care professionals, who are trained to be objective, have the same emotions when it comes to this type of care for their own family members.

**3. Can you get training?** Remember that even if you get some training on operating a machine or monitor in the hospital, you may receive a different type or model once you get home. Further training may be available in the community through a home care nurse, the Red Cross, or another agency.

**4. Who can you call with questions?** Ask the doctor or pharmacist about medication questions. Home medical technology companies usually have a toll-free number to call but the helpfulness of the responses may vary. Don't be afraid to ask questions and to ask for more help understanding the answers.

**5. How will you cope with providing this type of care – not just now, but in the long term?** You may be proud of your ability to manage the complexities of medical care and keep your family member at home, but you may also feel depressed, anxious and isolated. These are normal reactions — and were common among surveyed family caregivers — but it is important to recognize that extended periods of negative feelings affect not only your mental health but also your physical health. Consider what options might be better for you and ultimately for your family member.

*Adapted with permission from Carol Levine. A full version of this article is available at <http://www.aarp.org/home-family/caregiving/info-09-2012/im-a-caregiver-but-feel-like-a-nurse.html>.*

*To read more about nursing tasks and family caregivers, read a new report by AARP and the United Hospital Fund at <http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html> or <http://uhfnyc.org/publications/880853>.*

## Alzheimer's Notes

## Area Caregiver Publishes Book

Martha Stettinius is a central New York resident and author who took on the role of caregiver for her mom when she developed dementia. She has recently published *Inside the Dementia Epidemic, A Daughter's Memoir*.



It is a compelling read. At various points in the book, Martha writes “If I only knew then, what I know now” and then shares information that can benefit readers who may find themselves in similar situations in the future. Stop by our new offices (after January 15) to view this and other books in our family caregivers’ lending library:

*Inside the Dementia Epidemic: A Daughter's Memoir*, Martha Stettinius, Dundee-Lakemont Press, 2012.

## Spotlight on Advocacy

The Long Term Care Community Coalition (LTCCC) in New York State is devoted to improving care for the elderly and disabled. It recently has been working with consumer representatives from around the country to advocate against the inappropriate use of antipsychotics on individuals with dementia which it perceives is a pervasive problem, particularly in nursing homes.

As part of this advocacy, consumer representatives have worked with U.S. Senate leaders to introduce legislation that would improve requirements around informed consent for the use of antipsychotics on individuals with dementia. S. bill 3604 would require nursing homes to obtain informed consent before an antipsychotic medication is prescribed for a resident with dementia where the patient or an individual with legal authority to act on their

behalf, know the risks of a medication or a procedure and have a choice. It would require providing clear information about possible side effects and risks, as well as any alternative treatments, including non-drug interventions.

You can read more on this issue on the LTCCC website at [www.ltccc.org](http://www.ltccc.org), including how to send a message to your senator about this legislation if you so choose.

## Early Stage Dementia Programs

The Alzheimer’s Association will be offering two programs in Tompkins County this winter, one for persons with early stage dementia, and one for their caregivers/partners/friends which will run concurrently at:

**Kendal at Ithaca**  
**Mondays, February 18, 25,**  
**and March 4**  
**3:00-4:30 PM**



### **Living With Alzheimer's: for People with Alzheimer's**

The diagnosis of Alzheimer’s disease is life-changing and leads to many questions. This 3-part series is designed to provide your loved one with the knowledge, tools and strategies needed to cope when a diagnosis is made. It is strongly recommended that they attend all three sessions.

### **Living With Alzheimer's for Caregivers: Early Stage**

In the early stage of Alzheimer’s disease, families face new questions as they adjust. This three-part series is designed to provide care partners with the knowledge, tool and strategies needed to cope with a diagnosis of Alzheimer’s or related dementia. It is strongly recommended that you attend all three sessions.

Preregistration is required for both programs. Call Jessica Cornell at 607-785-7852 ext. 119 or email her at [jjcornell@alzcnny.org](mailto:jjcornell@alzcnny.org) to register or to be sent a content overview of each of the classes.

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

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

**Telephone:** (607) 274-5492

**E-mail:** [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org)

**Katrina Schickel, Project CARE Coordinator**

**Telephone:** (607) 274-5491

**E-mail:** [kschickel@tompkins-co.org](mailto:kschickel@tompkins-co.org)



## Websites of Interest to Family Caregivers:

**Tompkins County Office for the Aging:** [www.tompkins-co.org/cofa](http://www.tompkins-co.org/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)

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

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