



# ***In Support of Caregivers***

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

Summer 2013

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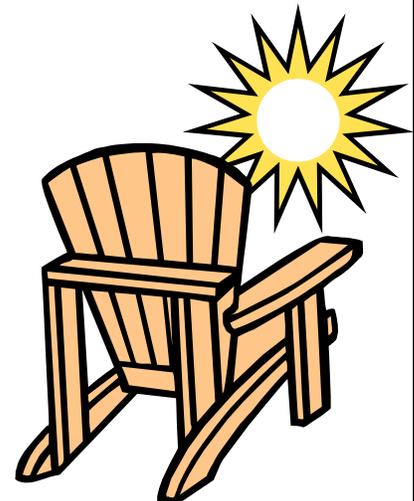
## ***In this issue:***

- ⇒ **Saying “No” – and Feeling Guilty**
- ⇒ **Be Good to Yourself**
- ⇒ **Overnight Respite Stays**
- ⇒ **Kitty Lane Family-Type Home**
- ⇒ **Answers to Medicare Questions**
- ⇒ **Upcoming Dementia Workshops**

## ***The Caregivers' Resource Center***

*Striving to support those who are caring for family and friends*

- Telephone support available Monday through Friday, 8:30 AM to 4:30 PM
- Referrals to respite services and other community-based services for caregivers and their care-receivers
- Volunteer Support for Caregivers through Project CARE
- \*This quarterly newsletter: *In Support of Caregivers*
- Powerful Tools for Caregivers* classes
- \*Directory: “Resources for Caregivers in Tompkins County”
- Caregiver Support groups
- Periodic workshops for family caregivers
- Alzheimer's education and support
- Lending library of books and videos on caregiving topics
- Speakers available to talk to community and employee groups on caregiving topics



**\*These publications are also available on-line at: [www.tompkins-co.org/COFA](http://www.tompkins-co.org/COFA)**

**(Click on “Local Resources for Older Adults” or “Newsletters”)**

# Summer Support Groups

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



## Bi-weekly Caregiver Support Group Meeting

- Open to those caring for parents, spouses or other elderly relatives or friends.
- (Note: This group will **not** meet during the summer. Next meeting on 1<sup>st</sup> Thursday of September.)
- 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**  
(June 25, July 23, Aug. 27)
- 1:00 – 2:30 PM in the Office for the Aging Conference Room  
214 W. Martin Luther King, Jr./State St.

## Evening Alzheimer's Group

In addition to the daytime group (above), people caring for loved ones with Alzheimer's or related disorders can also attend a group that meets at 6:00 PM on the 1<sup>st</sup> Wednesday of each month at Lifelong, 119 W. Court St.. Because of the holiday, the July meeting will be held on Wed., July 10. For information, call the Alzheimer's Association at 785-7852 ext. 119.

# 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 (273-7494)



A caregiver counselor will meet with family caregivers at their home, his office, or elsewhere and help them work through complex caregiving issues or for emotional support. This program also offers respite aide service (for a fee) to give caregivers a needed break. Reduced rates (sliding scale) available upon request.

## 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.

# Saying “No” – and Feeling Guilty

**Q** *How do I stop feeling guilty when I have to say no to my parents?*

**A** Learning to say no without feeling guilty is a process most of us go through many times in our lives. Saying no to parents, children, friends, and even co-workers can be difficult. Yet, setting limits about what you are able to do for your parents is important.



The first step in reducing guilt is to identify and understand why this emotion is paired with saying no. Ask yourself—Do I feel guilty when I say no to anything or anybody? How do my parents act when I say no? Are they angry, sad or understanding? Am I somehow turning feelings of disappointment (that I wasn't able to help) into feelings of guilt? Where do my feelings of guilt stem from—my parents or myself?

By first examining your feelings of guilt, you are in a better position to make changes. Talking with other family members, including your parents, about your feelings can help reveal some of the roots of your guilt feelings.

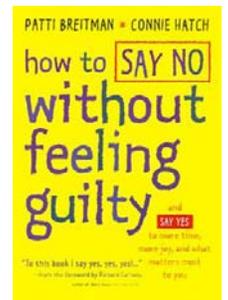
However, understanding why you feel guilty does not stop the feelings. So, resolve to notice the next time you say no whether guilt feelings are cropping up. If they do, try substituting the word “disappointed” for guilty. Notice whether it describes your feelings more accurately. Do I just wish things could be different (rather than thinking I am doing something wrong)?

Remember change is often slow and painful, but also rewarding. Reducing your guilt is a step toward strengthening your relationship with your parents.

Sometimes “no” can be more helpful to your parents than “yes.” Trying to do everything for them can make you feel resentful and diminish the quality of the time you spend with them. In some instances, saying “yes” all the time can make a parent more dependent than they need to be, and less confident in their own abilities. Whether it is just communicating your limits, or perhaps saying no to avoid encouraging unnecessary dependency, speaking truthfully, even when your response is “no” can improve your relationship in the long run.

Sometimes our present guilt feelings are bound up with remembering past mistakes we've made in our relationships. We may even still feel guilty about doing something that we didn't know was wrong at the time.

It's important not to confuse guilt with regret. Guilt results from doing something that we knew was wrong at the time. Regret comes from later learning that we could have done something better. When we understand the difference between guilt and regret, we can move beyond blaming ourselves for what we didn't know or weren't able to do at the time. One specific regret that many caregivers have is that they promised never to place their parent in a residential care facility.



Give some thought to these perspectives the next time you say “no.” You may feel less guilty each time you affirm that you are doing the best you can (or did the best you could in the past). You might then allow yourself to feel sadness, disappointment, or regret without “irrational guilt” short-circuiting your grieving process, guilt that can prevent you from working through your grief to a more serene acceptance of what you cannot change about your loved one's situation.

# Be Good to Yourself

**A**s a caregiver, taking the time to be good to *you* should be a priority. If you care for yourself first, then you can have the energy, strength and determination to take good care of your loved one.

It would be great if all of us could escape to the beaches of a tropical island to reenergize. But the reality for many caregivers is that they do not have the time to take a one- or two-week vacation during the course of the caregiving months or years. What becomes most important, then, is for you to do “little things” to take care of yourself every day to prevent the stress and strain of caregiving from creeping into your life and taking control of your mind, body and spirit.

Consider the following ways to get some much-needed “me” time:

## At Home Every Day...

- Find or create a “My Care Space” in your home that you can call “your own” at the beginning and end of your caregiving day. This space can be an entire room or a nook someplace. It should include something that is very special to you, such as a book, a flower, a picture, a pebble, a coin...
- Start and end your day by going to your “My Care Space” for five minutes to do one or more calming activities. These could include meditation, thinking positive thoughts, reading something uplifting like a greeting card or a few sentences from a favorite book, writing your morning/evening thoughts in a journal, or closing your eyes and breathing deeply.



## While You Are Caregiving...

- Develop a daily work schedule that includes a three-minute “mental pause” every hour,

during which you relax, and mentally—not physically—remove yourself from the current situation as much as possible.

- Consider including your loved one in some of your relaxation activities if he or she is capable of participating and would find the mental pause relaxing. Do something fun: sing a song, or hum; tell a funny story; listen to music; say a gratitude prayer; or breathe deeply five times, using inhale and exhale movements.

## And Routinely,

- Visit your doctor regularly for checkups and more often if you are frequently ill.
- Take an overnight vacation no farther than an hour’s drive away; check into a nice hotel and pamper yourself.
- Connect with agencies in your community that offer respite care so you can take a break from caregiving responsibilities. Use the few hours to sit in the park, see a movie or walk around the mall...
- Stay in touch with friends and family who have an interest in your well-being.
- Practice saying the word “Help!” Let people know when you need help, and ask for it.



*(Written by Geneva Cannon, a former caregiver for her mother and author of “Caring for Your Loved One Who is Ill at Home.” Reprinted with permission from the Spring 2013 issue of **care ADvantage.**)*

## Overnight Respite Stays

Respite care is planned short-term substitute care that frees up a family caregiver so s/he can get a needed break from caregiving, attend to their own health care needs (e.g., scheduled surgery), travel to a family function or for other reasons.

As an alternative to arranging for in-home substitute care, family caregivers sometimes find it best to arrange for a short-term respite stay in an assisted living facility or nursing home. Short-term stays are allowed in many residential care homes on a space-available basis.

For an assisted living stay, respite residents must have enough self-care skills to qualify, depending on the level of care offered at the residence.



Respite care can be provided for just overnight or for up to one month in duration, depending on the policy of the particular residence, as well as your needs.

Assisted living residences in Tompkins County include Longview, Sterling House, Clare Bridge, and Bridges Cornell Heights. Family-type homes in Tompkins County many also allow respite stays (Deer Haven, Evergreen House, The Old Hundred, and Kitty Lane).

If space is not available locally, you may want to look at options in nearby counties. Elizabeth Brewster House and Walden Place in Cortland County have recently contacted us to encourage inquiries about respite stays. Call the Caregivers' Resource Center at the Office for the Aging (274-5492) for contact information about any of the above residences or other adult care

residences within about a 45 minute radius of Ithaca.

## Kitty Lane

The latest residential care home to open in Tompkins County is called "Kitty Lane." It is a licensed "family-type home" which means it is certified by the NY State Health Department to be able to provide 24-hour supervision, personal care as well as room, board, and laundry services in a family living situation. Family-type homes are restricted by NY State to offering personal care to a maximum of four residents. This limitation, along with the operator living with the residents, is what makes it a family-type residential care home.



Kitty Lane is located between Dryden and Cortland at 58 Gee Hill Rd., Dryden, NY. The proprietor is Audrey Feint, who is a licensed RN. The brochure for Kitty Lane says residents "Must Like Kitties."



In addition to taking long-term residents, Kitty Lane will consider requests for short-term respite stays.

Residential care services and supportive care are bundled into a monthly charge. Third party payment possible for those in receipt of Supplemental Security Income (SSI).

To inquire, call Kitty Lane at 607-299-4936 or cell (607) 339-6406.

## News and Notes

### The New Old Age

Paula Span writes a regular column about “Caring and Coping” with family caregiving as part of her NY Times “The New Old Age” series. Recent column titles include “The Reluctant Caregiver,” “Reassurance for the Constant Caregiver,” and “Trapped in the Hospital Bed.” Another column might be appreciated by family caregivers relating to stepfamilies and other blended families titled: “In Blended Families, Responsibility Blurs”. Ms. Span has a way of expressing sentiments that many family caregivers feel, and makes many useful suggestions. You can review her columns online at <http://newoldage.blogs.nytimes.com/>.



Author: Paula Span  
Photo Credit: Emma Span

are willing to provide those services. Arrangements are made directly by the person seeking help with the person willing to provide the services. Call Cheryl Baker, Registry Coordinator, at the Finger Lakes Independence Center, 272-2433.

### VA Caregiver Support

For an overview of Caregiver Support Services offered by the Veterans Administration, go online to [www.caregiver.VA.gov](http://www.caregiver.VA.gov).

The toll-free number for the National Caregiver Support Line, sponsored by the VA, is 1-855-260-3274. The Caregiver Support Coordinator for our area is Cheryl Cox, Syracuse VA, (315) 425-4682.



### MV-1 Taxi Service Hours

Wheelchair accessible taxi service hours are now Monday-Thursday, 6:00 AM-6:00 PM. Friday, 6:00 AM-8:00 PM and Sunday to Thursday evenings, 6:00 PM-2:00 AM. Service beyond these hours is available with a 48 hour reservation and subject to availability of the taxi. For Friday night rides from 6:00-8:00 PM, call 2 hours in advance! To request a ride for your loved one in their power or standard wheelchair on the MV-1 Taxi, call Ithaca Dispatch at 607-277-7777. Regular taxi fares apply. Room for 4 (3 seated & 1 wheelchair) passengers.



### New Family Caregiver Guide & Checklist on Planned Surgery

Many older adults have planned surgery, such as hip or knee replacements, gall bladder removal, or heart bypass. Surgery can improve function and quality of life, but it also entails risks. *A Family Caregiver's Guide to Surgery for Older Adults* suggests what to ask the surgeon about treatment goals, pain, and physical limitations after surgery, as well as costs and post-discharge options. It also includes a checklist, adapted for family caregivers, from the American College of Surgeons and the American Geriatric Society to assess older patients before surgery. This checklist asks questions about the person's cognitive status, history of falls, nutritional status, and other elements that may affect the surgery and its outcome. Go online to [www.nextstepincare.org/Caregiver\\_Home/Elective Surgery](http://www.nextstepincare.org/Caregiver_Home/Elective_Surgery) to read the guide.



### Registry Referral Service

The Registry is a free referral service linking individuals seeking independent employment to people who need care in their home (companion, housekeeper, errands, yard work, personal care, LPN, RN). Call to receive names of people who

## WHERE TO GET YOUR MEDICARE QUESTIONS ANSWERED

<p><b>1-800-MEDICARE</b> To get general or claims-specific Medicare information and other important telephone numbers.</p>	<p>1-800-633-4227 TTY 1-877-486-2048 <a href="http://www.medicare.gov">www.medicare.gov</a></p>
<p><b>State Health Insurance Assistance Program (SHIP)</b> To get free Medicare counseling and personalized help making coverage decisions; information on programs for people with limited income and resources; and help with claims, billing, and appeals.</p>	<p>For contact information for SHIP programs by state, you can start your search at: <a href="http://www.medicare.gov/contacts">www.medicare.gov/contacts</a>. This site provides a "Find Helpful Contacts and Websites" tool for various organizations, including SHIP programs OR call 1-800-MEDICARE</p>
<p><b>Social Security</b> To replace a Medicare card; change your address or name; get information about Part A and/or Part B eligibility, entitlement, and enrollment; apply for Extra Help with Medicare prescription drug costs; ask questions about premiums; and report a death.</p>	<p>1-800-772-1213 TTY 1-800-325-0778 <a href="http://www.socialsecurity.gov">www.socialsecurity.gov</a></p>
<p><b>Coordination of Benefits Contractor</b> To get information on which insurance pays first and to report changes in your insurance information.</p>	<p>1-800-999-1118 TTY 1-800-318-8782</p>
<p><b>Department of Defense</b> To get information about TRICARE for Life and the TRICARE Pharmacy Program</p>	<p>1-866-773-0404 or TTY 1-866-773-0405 1-877-363-1303 (Pharmacy) TTY 1-877-540-6261 <a href="http://www.tricare.mil/mybenefit">www.tricare.mil/mybenefit</a></p>
<p><b>Department of Health and Human Services Office of Inspector General</b> If you suspect Medicare fraud. <b>Office for Civil Rights</b> If you think you were discriminated against or if your health information privacy rights were violated.</p>	<p>1-800-447-8477 TTY 1-800-377-4950 <a href="http://www.stopmedicarefraud.gov">www.stopmedicarefraud.gov</a> 1-800-368-1019 TTY 1-800-537-7697 <a href="http://www.hhs.gov/ocr">www.hhs.gov/ocr</a></p>
<p><b>Department of Veterans Affairs</b> If you are a veteran or have served in the U.S. military.</p>	<p>1-800-827-1000 TTY 1-800-829-4833 <a href="http://www.va.gov">www.va.gov</a></p>
<p><b>Office of Personnel Management</b> To get information about the Federal Employee Health Benefits Program for current and retired Federal employees.</p>	<p>1-888-767-6738 TTY 1-800-878-5707 <a href="http://www.opm.gov/insure">www.opm.gov/insure</a></p>
<p><b>Railroad Retirement Board (RRB)</b> If you have benefits from the RRB, call them to change your address or name, check eligibility, enroll in Medicare, replace your Medicare card, and report a death.</p>	<p>Local RRB office or 1-877-772-5772</p>
<p><b>Quality Improvement Organization (QIO)</b> To ask questions or report complaints about the quality of care for Medicare-covered services or service ending too soon.</p>	<p>Call 1-800-MEDICARE to get the telephone number for your QIO.</p>

Source: Medicare & You 2011 Handbook [www.medicare.gov](http://www.medicare.gov)  
Provided by Society of Certified Senior Advisors® [www.csa.us](http://www.csa.us)



# Why Is It So Hard to Ask for Help?

**M**any caregivers, especially those caring for spouses and partners, are reluctant to ask for help. Both care partners then are at risk if the caregiver's health suffers.

## Reaching Out for the Help You Need

**Why is it so hard to ask for help?** What's a good response to the statement, "Call me if you need me?" Despite the fact that family caregivers are drowning in responsibility or are really confused about what the next step ought to be, they often respond "no thanks" when help is offered. Asking for and accepting help is a complex issue. Obviously you first need to admit that having some help will make a real difference in your loved one's quality of life, and therefore yours as well.

Then you need to define what help you need. Which tasks would be the easiest to ask others to do? Which do you really want to do yourself? Which, if any, can you afford to pay others to do? If this sounds just like more work, know that it doesn't have to be an overwhelming task-- just a way to organize the thoughts and information you already have. Ready to give it a try?

## SIX STEPS to getting help.....

**1. Recognize that caregiving, like any job, is made up of lots of individual tasks,** not all of which are of the same importance. Some tasks take a few minutes; some may take many hours. Some are easy; others require skill and fortitude. The challenge is to know the difference.

**2. Recognize that asking for help is a sign of strength** and not of weakness. It means you truly have a grasp on your situation and have come up with a proactive problem-solving approach to making things easier and better.

**3. Create a list of the tasks that need to be done in any given week,** or at least those you are most concerned about, such as balancing your responsibilities at work with taking mom to

the doctor and Susie to soccer practice, bathing and

dressing your husband, cooking, cleaning, etc. When you see how long the list is you'll quickly understand why you are so tired and don't have time for yourself.

**4. Group your tasks into categories** such as personal care tasks for your loved one, transportation, and household chores. Group tasks into only a few broad categories, or many specific ones. There's no right or wrong way.

**5. Write down your caregiving worries.** Where will we get the money to pay for John's medications? Who will care for mom if I get sick? Where can I find an adult day facility that provides transportation? Seeing them in black and white helps diffuse some of their emotion. It also allows you to think more rationally about your concerns and understand how getting help with some of your tasks might lessen the stress. It can provide the basis for deciding which tasks you might ask a neighbor, family member, or the church to help out with, which you are willing and able to pay someone else to do, and for which there might be a public program.

**6. Share your lists with someone you trust** before you actually reach out for help—a friend, therapist, or clergy person, perhaps. The intent is to first get comfortable with the idea of talking about your need for assistance and hopefully getting some encouragement and good ideas in the process. Then take a deep breath and actually ask someone to help with one of the tasks on your list, or ask for guidance in resolving your most persistent worry. Start with something small, especially if you are looking for hands-on assistance or something that requires someone doing you a favor. Don't get discouraged if you get rejected at first. It sometimes takes perseverance. Just remember—the effort is worth it because the goal is to better care for your loved one and yourself.

*Reprinted with permission of the Caregiver Action Network. Visit their website at*

[www.CaregiverAction.org](http://www.CaregiverAction.org) for additional ideas and support.

## Alzheimer's Notes

### Upcoming Alzheimer's Workshops

Both of the following workshops will be presented by Jessie Cornell of the CNY Alzheimer's Association.



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

**When:** Wed, June 26, 12:30pm – 4:00pm

**Where:** Cortland County Office Building  
(Activity Room)  
60 Central Ave., Cortland

**Description:** When someone is diagnosed with Alzheimer's, friends and family have many questions. This presentation is designed to provide caregivers with the knowledge, tools and strategies needed to cope with a diagnosis of Alzheimer's or related dementia. Reservations required. To register, or for more information, call 607-785-7852 ext. 119 or email [jjcornell@alz.org](mailto:jjcornell@alz.org).

#### *Basics of Alzheimer's Disease & Dementia*

**When:** Wed., July 31, Noon-1:30 PM

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

**Description:** 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, contact David Stoyell at the Office for the Aging, 274-5492, or email [dstoyell@tompkins-co.org](mailto:dstoyell@tompkins-co.org).

### Online Discussion Groups

Family Caregivers can benefit immensely from contact with other family caregivers. In addition to support groups and other family caregivers you may know, online caregiver discussion groups provide a valuable way to connect with other family caregivers. You can find several such groups online searching for “Caregiver Forums” or “Caregiver Discussion groups” or “message boards.”

You can search for discussions on topics that are of interest to you. Other caregivers may have already asked the same question that you have, and you can read responses that have already been posted. You can also post your own questions.



You can check out the Caregiver Forum sponsored by the Caregiver Action Network by visiting their website at [www.caregiveraction/forum](http://www.caregiveraction/forum).

The Alzheimer's Association also sponsors a variety of “message boards” including a “Caregiver Forum,” a group for those with Alzheimer's, a group discussing clinical trials, and other specific interest groups. Check them out at [www.alzconnected.org/discussion.aspx](http://www.alzconnected.org/discussion.aspx).

# 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.

**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)

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

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

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