



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 2013

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First Thursday Caregiver Meetings

In the past year, our general caregiver group had a strong preference for meetings which included a guest speaker presenting on a topic of interest to family caregivers. So we will continue to offer monthly meetings on the first Thursday evening of each month with a guest speaker. We have discontinued the less popular general sharing meeting which had been held on the 3rd Thursday of each month. The location of the First Thursday meetings has been moved to Office for the Aging in its new location. Please mark your calendar for topics which interest you:

Upcoming First Thursday Speaker Meetings

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

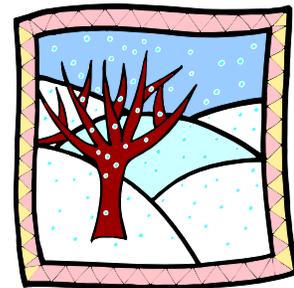
November 7, 6:30-8:00 PM: ***“Person-Centered Dementia Care”***
Speaker: Martha Stettinius

December 5, 6:30 -8:00 PM: ***“Legal and Financial Issues for Caregivers”***
Speaker: Joy Blumkin

January 2, 6:30-8:00 PM: ***“Housing Options for Seniors”*** Speaker: Dave Stoyell

See page 3 for more details about each of these presentation and the speakers.

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. It will meet a week earlier, December 17, to avoid conflicting with the Christmas holiday.



Fall Caregiver Meetings

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



Caregiver Group Meeting

- Monthly meetings with a guest speaker presenting on a topic of interest to family caregivers. Note: this is not a “support group.” It is open to anyone interested in the topic.
- Meets the 1st Thursday of each month. (Nov. 7, Dec. 5, January 2)
- 6:30-8:00 PM in the Office for the Aging Conference Room, 214 W. Martin Luther King, Jr/State St.

Alzheimer's Support Group

- Open to those caring for loved ones with Alzheimer's or other cognitive impairments
- Meets the 4th Tuesday of each month (October 22, Nov. 26, Dec. 17 – note the December meeting is a week early because of the Christmas holiday.)
- 1:00 - 2:30 PM in the Office for the Aging Conference Room, 214 W. Martin Luther King, Jr/State Street

Evening Alzheimer's Support 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 1st Wednesday of each month at Lifelong, 119 W. Court Street. 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

Margaret Page (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 to give caregivers a needed break. Reduced rates for this service (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.

Upcoming Presentations for Family Caregivers

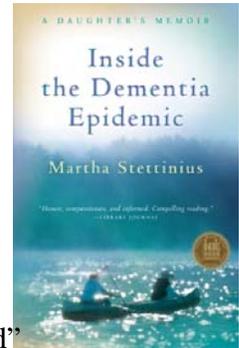
Workshops offered by the Caregivers' Resource Center

The following presentations are offered free of charge at the Office for the Aging (214 W. Martin Luther King, Jr./State Street). Free parking is available at that time on the street and in the lot behind the Office for the Aging. *Pre-registration is encouraged, but not required. Call 274-5492 or email dstoyell@tompkins-co.org.*

Person-Centered Dementia Care

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

Presented by: Martha Stettinius



Martha Stettinius will talk about how caring for someone with dementia need not be a “long good-bye,” as it’s so often called, but can be a “long hello” as you learn to communicate and enjoy the company of your loved one through the final stages of the disease. She will talk about seeing the person with advanced dementia as still “here,” capable of sharing and receiving love and affection, and why “person-centered” dementia care is so important. Martha’s new book, "Inside the Dementia Epidemic: A Daughter's Memoir," recounts her experience over eight years as a “sandwich generation” caregiver for her mother, at home, in an assisted living facility, a rehab center, a “memory care” facility, and a nursing home.

Legal and Financial Concerns for Caregivers

Thursday, December 5, 6:30-8:00 PM

Presented by: Joy Blumkin, Esq.

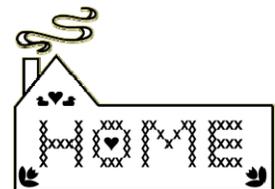


Joy Blumkin, a local elder law attorney, will address common legal and financial concerns of the elderly and their caregivers such as planning for the expense of long-term care and planning for incapacity (advance directives, guardianship).

Housing Options for Seniors in Tompkins County

Thursday, January 2, 6:30-8:00 PM

Presented by: David Stoyell



David Stoyell, the Coordinator of the Caregivers' Resource Center at the Office for the Aging, will discuss the range of Senior Housing Options in Tompkins County, from homeownership through Independent Living Senior Housing through Residential Care Options, and the extent to which each of them can meet the housing needs and social preferences needs of older adults as they seek to “age-in-place” in the least restrictive environment possible.

What Can You Do about Caregiver Burden?

Caring for a family member or friend can be tremendously fulfilling. It can bring you closer together and fill your heart with love. Yet caring can also take a toll on your physical and mental health, on finances, personal relationships, and work life.

The stress that caregivers experience is often long-term, uncontrollable, and unpredictable. It can develop into caregiver burden: the depletion of physical and emotional well-being that comes from giving for too long without taking time to replenish your energy. Half of caregivers report moderate to high levels of caregiver burden.

You know you have caregiver burden if you feel:

- a loss of privacy or time for yourself
- stressed by juggling caregiving and other responsibilities
- angry or strained when around the one receiving your care
- unsure about what to do about the person in your care
- guilty about not doing enough, or not doing well enough as a caregiver
- your social life or relationships with family or friends have suffered
- your physical or emotional health has suffered
- you've lost control of your life

As these feelings become more intense and persistent, your level of burden and the risk to your health grows. Others need your care, and quitting isn't an option. What can you do about caregiver burden? There is a story by an unknown author circulating on the web that speaks to this question:

When presenting a stress management class, the

teacher raises a glass of water. Everyone expects to be asked the ultimate question, "Half-empty or half-full?" But she fools them all by instead asking, "How *heavy* is this glass of water?" Answers from the students range from 8 ounces to 20 ounces. With a knowing smile, the teacher replies, "The *weight* doesn't matter. Its heaviness depends on the *length of time* I try to hold it."

"If I hold it for a minute, that's no problem; it will feel light. If I hold it for an hour, that's a problem. My arm will really hurt. If I try to hold it for a day, that's a disaster! I'll need an ambulance! In each case, it's the same weight, but the longer I hold it, the heavier it becomes."



That's the way it is with caregiver burden. If you give what seems like a manageable amount of care for too long without a break, the load grows increasingly heavy. Sooner or later it becomes more than you can bear, and no matter how much you want to, you won't be able to carry on.

Like that glass of water, periodically you have to put caregiving responsibilities aside to rest. It's the only way to refresh your energy and retain your strength for the long-term commitment of caregiving.

So think about what restores your energy. What brings you joy? Whose company is energizing? What pastimes are enlivening? What natural scene restores your balance? What habits restore your good health? What helps you relax? What fills you with gratitude? Build these experiences, people, pastimes, and habits into your day-to-day life. No matter how small, these will be good for both you and your loved ones.

(Article written by Jane Hamilton for the August 14, 2013 issue of "Aging in Action" newsletter, Mathers Lifeways. You can subscribe to it at www.aginginaction.com.)

News and Notes

Transportation to/from Surgery

Occasionally, people can't have procedures at the hospital because they have no one to drive them home after being on anesthesia. Comfort Keepers, a local home care agency, provides transportation to and from medical appointments for its clients. Round trip cost of \$125 includes an hour of care in the home to assure the client is back home safely inside, has a meal if needed, and is comfortable. It is not a taxi service and people must be willing to do intake required of all their home care clients. Paperwork needs to be filled out prior to, or the morning of, the surgery. Service is currently available for appointments in Tompkins County. For more info, call Comfort Keepers at 272-0444.



Behavioral Interventions for Depression in Cognitively Impaired Elders

The Ithaca College Gerontology Institute is sponsoring an afternoon workshop on November 19 from 2:00-4:30pm by led by Cassandra Bransford from SUNY Binghamton. She will share insights from her research on depression in older adults with cognitive impairments and teach participants how to turn them into practical applications for behavioral interventions in health and human service settings. Family Caregivers are also welcome. (Cost: \$25 or \$15 for retired individuals). Register online at ithaca.edu/agingworkshops or email aging@ithaca.edu (phone: 274-1965) if you have questions.



Downsizing Help

Some are overwhelmed at the prospect of having to dispose of possessions and deal with other aspects of a moving to a smaller home or apartment. Longview, a local senior living community, has links on its website to a number of helpful articles on downsizing as well as a list of professionals who can provide help with downsizing. Check them out online at www.ithacarelongview.com/downsizing-help.html or call the Caregivers' Resource Center of the Office for the Aging to be sent printed materials (274-5492).



US against Alzheimer's

Community Is a Facebook group for both individuals with Alzheimer's, and family members and friends of people with Alzheimer's and other dementias. It's a venue for people to share their questions, tips, thoughts and advice, and seek the same from their peers. One of the moderators is Martha Stettinius who will be speaking at our November 7 workshop (see p. 3). To learn more, visit the Facebook page at www.facebook.com/groups/usagainstalz/.



New to Family Caregiving? AARP

AARP publishes a planning guide geared to those who are preparing to care for aging parents. For a free copy, call AARP at 1-877-333-5885 and ask for publication D18758 titled "Prepare to Care." Also, visit the AARP online Caregiving Resource Center for information, tools and tips for caregivers (www.aarp.org/caregiving).



Starting a Conversation about Long-Term Care

My Dad was diagnosed with Alzheimer's in his 50's. Mom had to provide home care and then facility care for him for the ten years before he died. Despite this experience, when I proposed to my younger siblings that we ought to now talk with our mom about her preferences should she need long-term care in the future, I initially was pooh-poohed: "Mom's going to outlive us all" and "We don't need to talk about that now."

However, most people will need considerable assistance with activities of daily living (long-term care) for many months and some for many years. Can such care be reasonably expected to be received where they are living now? What paid care might be needed and will it be affordable? Is everyone assuming that Suzy will take care of mom? Has anyone talked to Suzy or Mom about these assumptions?

Although these conversations may not be comfortable, we may want to get issues out in the open. In broad terms we know that most everyone's wish is to live as independently as possible for as long as possible and "not to be a burden," but we can't really know someone's preferences and plans unless we've had good conversations with them.

Sometimes it is the older adult who encounters resistance from younger family members when broaching the topic; other times, a parent or other older adult may be reluctant to discuss possibly future dependence on others for help.

In either situation, the following tips may help in getting the conversation started and keep it going. (They are reprinted from the May/June 2013 issue of the *Cortland Senior News*.)

Tips for Getting the Conversation Started

1.) Use an example. Start by discussing the situation of another family member or perhaps a neighbor who is already receiving long-term care. Discussing the topic as it

relates to others make it easier to steer the conversation to yourself.

- 2.) Ask "What if" questions, such as "What if I can no longer drive?" or "What if I can't get my own meals?" The answers to these questions will encourage all to think through the consequences of decreased independence.
- 3.) Use the news media as a starting point. Mention that news report you just heard on the cost of nursing home care (or assisted living or home care), and ask your family for help looking at your finances to evaluate your options for paying for it.

Tips for Keeping the Conversation Going



- 1.) Do a lot of listening.
- 2.) Don't expect every little issue to be settled all at once. Financing, choice of long-term care, loss of independence, health concerns, and aging are all very complex issues.
- 3.) Be clear about why you want to talk about long-term care and its costs. Voice your concerns, and what you would like to see happen, and why.
- 4.) Be prepared for a lack of agreement and perhaps even resistance.
- 5.) Stay focused, and try to avoid being sidetracked onto other issues.
- 6.) Become informed on your options for long-term care; encourage your family to do same.

In all of this conversation, one goal of family members is to hear what is most important to their elders. If there is a trade-off that has to be made in the future, what losses are more significant to them than others? For example, is being in the family home (even if homebound and somewhat socially isolated) what is important?

Holiday Stress Assessment for Caregivers

If you are trying to balance eldercare challenges with self-care and the rest of life's opportunities and demands, spend a moment to think about your "holiday job list" before automatically trying to fit everything in. For each of the following, ask yourself: Would the holidays be the same (or better) without it? Do you do it out of habit, tradition, free choice or obligation? Is it a one person job, or can it be shared, or even delegated? Do you like doing it or is it a chore?

Decorating a tree...contributing to special funds...baking holiday cookies...going to parties (are some more important than others to you?)...Making homemade holiday gifts...sending holiday cards...doing holiday shopping...seeing people you never see any

other time of year...having the house clean...decorating different rooms of your home...providing "quiet-together" time for immediate family or other spiritual traditions...buying gifts for co-workers, service people...attending services, preparing traditional foods...

You can probably add to the list. Assess your stress level even thinking about some of these. Which will be a joy? Which will be well-worth dedicating some of your limited time? Which can be eliminated, delegated or deferred to a less demanding time of year?



Five Myths about Hospicare

Quality end-of-life care isn't about how you die; it's about how you live! Below are five myths some people may hold about Hospicare:

1. *Choosing Hospicare means that I'm giving up.*

When cure is no longer possible, Hospicare provides the type of care most people say they want at the end of life—comfort and quality of life. Very often, family members say "we wish we'd known about Hospicare's services soon."

2. *Hospicare won't allow me or my family to be involved in decisions about treatment.*

Hospicare puts patients and families at the center of care. Professional team members provide guidance and encourage honest communication about individual wishes/choices.



3. *I want care for my husband at home, not at the Hospicare residence.*

Hospicare is not a place, but a philosophy of care. The majority of hospicare's patients stay in their own home while receiving hospice care, surrounded by their family and familiar settings.

4. *My grandfather doesn't have private insurance, so he won't be able to afford Hospicare's services...*

Hospicare services are fully covered by Medicare, Medicaid, and by most insurance companies. In addition, the generosity of Hospicare's community donors ensures that no one is turned away for inability to pay.

5. *My partner's doctor suggested Hospicare. That must mean my partner has only days to live.*

Hospicare's services are available to anyone who has a life-threatening illness with a prognosis of six months or less to live if the illness runs its normal course. Patients can remain on Hospicare's services longer than six months, if necessary. They can also come off Hospicare's services if their illness should improve.

The Art of Accepting Help

Learning to accept help from others is an art. It takes skill, practice and talent. There is a right way to receive and a wrong way. Learning how to navigate walking on eggshells is tricky.

The minute you tell others that you or your loved one is very ill, they want to discuss or give advice. First, the questions come at you: “What can I do? What do you need?” How can I help? Can I watch your children for you? Can I bring you meals? Can I drive you to appointments? Can I have a fundraiser in your name?” These are wonderful gestures that you may not yet be ready to accept.

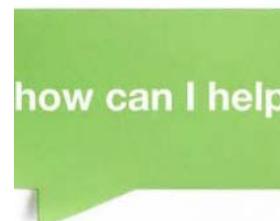
You and your loved one did not invite this illness into your lives, but people loved and care about you. Reflect on these questions for a while:

- If the situation were reversed, would you be reaching out to help those who want to help you now?
- Would you feel that they were a burden to you?
- Would you be seeking gratitude or paybacks?
- Would you be bringing them a meal or sending them a card?
- Would you gladly place money in an envelope for them, with no name to indicate who gave it?
- Would you take them to an appointment?
- Would you sit in a quiet room just to keep them company?
- Would you give them a hug, because your heart feels the urge?

These actions and reactions are ones many of us would offer to others and are good reasons to allow your friends and families to help now, so welcome their gestures. If people are reaching out to help, it is a compliment to you as a person...

In the future, you will probably come across someone with whom you have an opportunity to “pay it forward...” The greatest gift you can give to a human being is to allow them to give to you; the reward for them isn’t measured in anything other than their hearts.

After you share your news with your family and friends, keeping in touch with everyone may feel overwhelming. Here are some suggestions for maintaining order after sharing the news your loved one is ill:



- Set boundaries and explain to people that it will be too difficult to talk about everything on a regular basis. Let them know that you appreciate their support and will update them as your energy permits.
- Many people who are ill and their families create websites or blogs or send mass emails in order to update the people they care about. It gets exhausting to give the same updates over and over. Place your needs first
- Remember, it may have taken a lot of courage for them to reach out to you. Don’t ignore others’ kind gestures...People will be holding you in their hearts, and they will be feeling helpless. Allow them to receive updates (e.g., via email) and to send you messages filled with support.
- If updating through technology feels overwhelming, that is okay. Some people can appoint a close friend or relative to do this for them a regular basis.

During this difficult time, your needs come first. Your friends and family will understand.

[Excerpted with permission from an “Walking on Eggshells,” by Amy Sales, Summer 2013, issue of care ADvantage.
www.alzfdn.org/Publications/care_advantage/]

Caregiver Journaling

I came across information on journaling for therapeutic purposes while looking on the Internet for caregiver information. The practice has been used by professional caregivers, such as nurses and therapists, as a private way to vent the emotions that naturally occur through their caregiving duties and to come up with creative solutions to issues.

There are numerous websites dedicated to caregivers where people can read relevant articles and have the options of joining online discussion rooms if the topic is of interest. However, not everybody has a computer, or the time and inclination to do this. Some caregivers may have only 15 minutes in their day, broken into intervals, for their own personal time.

Journaling is a perfect fit as a creative outlet for the overwhelmed, overworked caregivers of today. It may cost you a dollar or less for a notebook. You can choose a moment to jot down your feelings, even if your time is not your own and you are at the mercy of your care receiver's needs. Allow your thoughts to come out uncensored. You end up telling your story and venting your feelings.

You may decide to tear up the piece of paper if you don't want anyone else to come across it. Wait at least twenty minutes if you do decide to destroy the paper so your brain can process the information. You may want to keep this page along with others to look back on. This will allow you to see patterns and become proactive, as well as recording your own personal history.

This creative act will boost your immune system and relieve stress the same way meditation and exercise do. The activity stands in the place of a trusted friend or sibling, somebody who knows your history and won't judge your feelings.

Readers might be interested in Lynn Brown's book, *You Want Me to Do What? Journaling for Caregivers*. (Ed. note: It can be borrowed from the Caregivers' lending library at the Tompkins County Office for the Aging or a gently used copy can be purchased for very little on Amazon.com).



ThoughtfulCaregivers.com is a website that I visit regularly. I saw a short on PBS that shared audio journals made by both caregivers and care receivers. Please think about this and read about this. Then, grab a notebook, or go on your computer or use a tape recorder, and give journaling a try.

(Written by Cinde Priano, Caregiver Services Coordinator for the Ontario County Office for the Aging. Reprinted from the agency's Summer 2013 caregiver newsletter.)

Medicare Notes

Medicare Open Enrollment is from October 15 to December 7 and is the time each year when older adults can change their health insurance coverage, with changes to be effective January 1, 2014. If you or your care receiver need assistance in comparing options, health insurance counseling is available from Lifelong (273-1511) and the Office for the Aging (274-5492).



Note: Medicare beneficiaries do **not** need to concern themselves about the new "NY State of Health," or other state health insurance exchanges. They are only for people who do not already have Medicare or other affordable health insurance through their employer.

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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Websites of Interest to Family Caregivers:

Tompkins County Office for the Aging: 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

Caregiver Action Network: www.caregiveraction.org

Next Step in Care: www.nextstepincare.org

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