



TOMPKINS COUNTY
OFFICE FOR THE AGING

Aging Better, Together



Winter 2018
Vol. 31 Number 4

In Support of Caregivers

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

In this issue:

***Caregiver Support Services**

***The Memory Maker Project**

***Tips for Advocating for Loved
Ones in a facility.**

***10 Tips for Caregivers During
the Holidays**

Local Caregiver Support Services

Caregiver's Resource Center & Project Care Services

Tompkins County Office for the Aging

Rodney Maine 274-5491

Caryn Bullis 274-5450

The Caregiver's Resource Center & Alzheimer's Support Unit offers family caregivers information, consultation services, workshops, this newsletter and a lending library of books on family caregiving topics. Stop by or call for an appointment.

Volunteers with **Project CARE** offer caregivers a needed break and help 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 Caryn to discuss your needs.

Caregiver Counseling
Family and Children's Services
Ann Dolan 273-7494

A caregiver counselor will meet with family caregivers periodically in her office to help them work through complex caregiving issues or provide emotional support. Special circumstances may be considered for in-home service. No charge. Donations accepted.

Adult Day Program
Longview Adult Day Community
Monday through Friday, 9am-3pm
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: \$55/day includes lunch and snack.

Support Groups



Caregiver Support Group
3rd Tuesday of each month
6:30pm-8:00pm
Family & 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 Caregiver Groups

1st Wednesday of the month at 5:30pm at Lifelong, 119 W. Court St., Ithaca. For information call the Alzheimer's Association at 330-1647

3rd Wednesday of the month at 12:30 at Walden Place, Cortlandville. Call 756-8101. Companion care for your loved one available during the meeting.67910

Cancer Caregiver Group

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

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

Parkinson's Caregivers Group

1st Monday of each month, 11:00am-12:30pm at The *Office for the Aging*. Call the Office for the Aging. 274-5491 for more information.



Art, culture and advocacy for people living with memory loss and their loved ones.
Christina@MemoryMakerProject.org
607.240.6204 | MemoryMakerProject.org

Fall 2018 Programs

The Memory Maker Project offers **free interactive cultural programs** so people living with Alzheimer's, other forms of memory loss, and their loved ones can engage and connect with each other through the arts. **Registration is required.** Call **607.240.6204** or e-mail **Christina@MemoryMakerProject.org**

DECEMBER

Out & About at the Arnot | Elmira

Thursday, December 6 | 2:00-3:00 pm
235 Lake St, Elmira

Out & About at Anthony Brunelli Fine Arts | Binghamton

Saturday, December 8 | 11:00 am-12:00 pm
186 State St, Binghamton

Meet Me at the Corning Museum of Glass | Corning

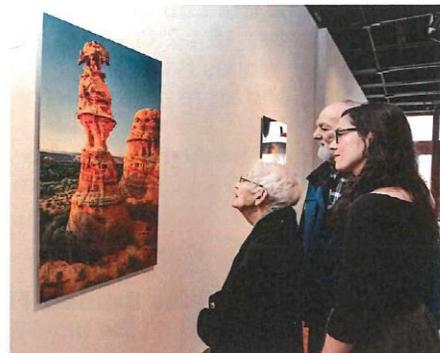
Monday, December 10 | 1:30-3:00 pm
1 Museum Way, Corning

Out & About at Roberson | Binghamton

Thursday, December 13 | 2:00-3:00 pm
30 Front St, Binghamton
Discuss holiday traditions, share stories, and sing along to holiday classics.

Out & About at the Johnson | Ithaca

Thursday, December 20 | 2:00-3:00 pm
114 Central Ave, Ithaca
A guided discussion about the Moon exhibit, featuring celestial East Asian artwork and poetry.



ONGOING

Memory Maker Gallery Open House

First Friday of each month | 6:00-9:00 pm
215 State St, Binghamton

Stop by the Memory Maker Project Gallery to snag prints featuring beautiful artwork lovingly made by artists living with memory loss, or swing by to say hello and learn about the Project!

SPECIAL EVENTS & LECTURES

Call, or visit our website to learn about upcoming special events and lectures.



Programs are made possible in partnership with the Broome County Office for Aging and with support from Triphammer Wine and Spirits, United Health Services, the Chenango Arts Council, Southern Tier Veterans Support Group, Community Foundation of Elmira-Corning and the Finger Lakes, Corning Inc. Foundation, United Methodist Homes and generous contributions from people like you.

Learn how you can support the Memory Maker Project at MemoryMakerProject.org

MemoryMakerProject.org | 607.240.6204 | 215 State St. Binghamton

Advocating for Your Loved One in a Facility: Your Role as Caregiver Remains Essential (Part I)

[Posted by Martha Stettinius on October 8, 2013 on Caregivers.com](#)

We are all caregivers whether our loved one lives in their own home, in our home, or in a facility. Whether we live down the hall from them, across town, or across the country, our role as their caregiver and advocate remains crucial.

Lots of times family members think “I’m not really a caregiver because my mom/dad/spouse/partner doesn’t live with me.” Have you ever thought that? I did, when I moved my mother, Judy, from my home into assisted living back in 2005. Feeling so much guilt about my decision, I thought, “Real caregivers take care of their loved ones 24/7 in their own home.” I also assumed that with Mom in assisted living, we could return to our independent lives, back to our old relationship of just mother and daughter, and that I wouldn’t have to do very much.

I was so wrong. My job as caregiver not only continued over the next 8 years Mom lived in dementia care facilities, but intensified in many ways. Your role, too, remains essential if your loved one moves out of their home or your home into a facility.

First, Let Go of the Guilt

We need to let go of that guilt—which almost everyone feels when their loved one is in a facility—and concentrate on how we can advocate for our loved ones. Often, the care they receive in a good facility is equal or better than what we can provide at home when we are overloaded, losing sleep, and risking ill health ourselves. So, let go of the guilt, and look for ways to improve your loved one’s quality of life wherever they are living. Instead of promising our loved ones that we will never place them in a facility, promise them that you will make sure that they will always receive the best care possible as their needs change.

Ways to Advocate for Your Loved One in a Facility (Part I):

To find a good facility, take some **tours**, but also try to **visit unannounced** to observe. If a place has an unpleasant odor, that is always a bad sign; a facility that runs smoothly will look and smell clean. If you are looking for a

nursing home, you can use the medicare.gov website to compare facility ratings for staffing ratios and other measurements of quality care. Look for a facility that believes in “person-centered care,” that treats individuals as unique people, not patients. Any facility that you consider should have an ambiance of human warmth, with staff members smiling, talking to residents, and offering hugs, for example. Don’t be fooled by a facility that looks like a plush, top-tier hotel; what’s most important is not the carpeting and furniture but your loved one’s quality of life as they interact with everyone from the aides to the administration. (If you are fortunate enough to live near a nursing home on the Eden Alternative registry or a Green House Project nursing home, I would recommend getting your loved one on their waiting lists, because they offer top-notch person-centered care even for people who run out of savings and have to go on Medicaid (as my mother did).)

- **If your loved one has dementia**, look for a facility that offers dementia-specific care (continence care, for example, and dementia-related activities) plus training in dementia care for the staff. (Laws requiring dementia care training for facility staff vary by state and type of facility.)
- When you take a tour of the facility, ask them to **clarify their guidelines** about when your loved one will have to move out (for example, if they become incontinent, need to be spoon-fed, or can no longer take a step to transfer from a wheelchair to bed). Look for clear communication and expectations. (If you are considering assisted living, here are some more questions you can ask them.)
- Once your loved one is moved in, if you live within driving distance, **visit at odd times**. It’s sad but true that a resident who has family visiting a lot may receive better care than a resident who never has visitors. (This is another reason to find a facility near you, even if it means moving your loved one from their state to yours.)

Advocating for Your Loved One in a Facility (Part II)

Posted by Martha Stettinius on October 15, 2013 on Caregivers.com

1. Don't be afraid to speak up—respectfully.

When Mom first moved into assisted living, I felt shy about speaking up on her behalf. I didn't want the staff to see me as a pain in the neck, and perhaps feel less kindly toward my mother because of me. But I got over that shyness, and I'm glad I did. If you approach the staff in charge in a respectful manner (picking your battles carefully, not fulminating over every little thing), they are usually responsive.

For example, when Mom first moved into assisted living, she was seated at meals at a table in the larger dining room with table mates who never said a word. Mom was very social, a talker. I couldn't bear to see her at this table three times a day, so I asked if she could be moved. After some hesitation, the care manager moved Mom into a smaller dining room, and Mom enjoyed the company of three women who were equally as talkative. She was happy with them, and seeing her with them brought a smile to my face. Don't hesitate to speak up for your loved one—in small ways like these, and about larger issues.

2. Join the facility's caregiver support group

If the facility has a caregiver support group or "family and friends council," join and share your concerns. My mother's nursing home had such a group, and we invited the director, nurses, dietary director, and other staff to come and speak to the group. If your loved one's nursing home does not have such a council or support group, ask the director if you can start one. It's a matter of the facility putting up flyers or sending out an email announcement. Having such a group in place is a powerful message to the facility staff that family members are paying attention and care deeply about their loved ones' quality of life from day to day.

3. Go to your loved one's care plan meetings

Every few months facility staff will hold a care plan meeting to review how your loved one is eating; behavior issues; any need for a higher level of care; any illness or conditions that are being treated; and whether or not

they are participating in activities. My mother's assisted living facility did not invite family members to their care plan meetings, but I participated in her care plan meetings in her memory care facility, rehab facility, and nursing home. If you can't attend in person, ask for a follow-up phone call to be updated.

4. Encourage the staff to include your loved one in activities

Mom was never a church-goer, but in her nursing home she enjoyed being wheeled to the weekly church service, where the minister knew her name and she could listen to the residents sing. If the facility includes family members in their care plan meetings, ask them what activities your loved one is being taken to, and what activities they particularly enjoy. Make it clear that your loved one should be a regular participant.

5. Talk about your loved one's end-of-life preferences

As your loved one's advocate, you will play a central role in end-of-life decisions. Talk to the facility staff at your loved one's care plan meetings about what your loved one's preferences would be, and make sure the relevant paperwork is on file (such as a DNR, Health Care Proxy, Living Will, and POLST form).

6. If needed, contact the facility's ombudsman

Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities and similar adult care facilities. If your concerns are not being addressed by the facility staff, contact your county's Office for the Aging to get the contact information for the facility's ombudsman. An ombudsman is usually a sympathetic person informed about elder care issues who can listen as you think through your concerns, help you approach facility staff, or intervene on your loved one's behalf.

7. Arrange for others to visit

And finally, you can help bring an extra spark of life to your loved one's days by visiting yourself, or arranging for others to visit. When Mom ran out of savings and had to move from her memory care facility to the nursing home, I hired one of her favorite aides from the memory care facility to visit Mom each week in the nursing home. I also hired a neighbor, a massage therapist who specialized in body work for elders, to visit Mom for a half hour each week. Despite Mom's advanced dementia, it was clear that she

knew these two women were special to her. I felt grateful that for a few dollars a week I could help Mom enjoy these friendships right through her final days. And these women served as extra “eyes and ears” to monitor Mom’s care.

Over my years of caregiving I never tried to be all that my mother needed, all by myself, and I think that both of us were better off for it. If caring for your loved one at home will not work for you, either, don’t feel guilty. You will remain their most important protector, advocate, and companion, and be able to enjoy their company more when you do see them.



Office of the State Long Term Care Ombudsman

Educating

Empowering

Advocating

Certified Long Term Care Ombudsmen provide free-of-charge advocacy to and serve as a resource for residents of long-term care facilities (nursing homes, assisted living and adult-care facilities).

Ombudsmen respond to a variety of concerns about long-term care including:

- Quality of care
- Abuse and neglect
- Rights violations
- Lost and stolen belongings
- Dietary concerns
- Discharge, eviction or termination of services
 - Public benefits programs
 - Cost of care

**For information or assistance, please call your local ombudsman
serving Tompkins, Chemung, and Schuyler counties
at 607-274-5498.**

10 Tips for Caregivers During the Holidays

Feeling stressed? Reset your expectations and enjoy the little moments

by Amy Goyer, AARP, November 19, 2018

For some family caregivers, the holidays can be a joyful time when spirits are lighter. It feels good to care for loved ones and enjoy time together, celebrating with family traditions. But for many the holidays also bring added stress — an already busy caregiver finds there's even more to do during the holidays. Something's gotta give! It's OK to give yourself a bit of a break this year. Here are some tips to help you make it through the holiday season with more joy and less stress.

1. Focus on what is most meaningful

As much as we'd like to create the perfect holiday experience, remember that perfection is not the goal of the holidays — meaning and joy are. There are many factors we can't control when it comes to our loved ones' health and abilities, so adjust your view of a successful holiday. Talk about prioritizing the holiday activities that hold the deepest meaning. Focus on what feels necessary to produce a holiday feeling and create good memories.

2. Simplify your holiday activities

If going all out for the holidays will push you over the edge this year, remember that it doesn't have to be all or nothing. If you can't put out all of your decorations, choose a few items that are most significant. You might ask a friend to decorate, or pay someone to do so; you can always rearrange decorations once they are out. If going to all religious services feels like too much, choose one service that means the most. If sending greeting cards is too time-consuming, try sending e-greetings. Many family caregivers also adjust the location of celebrations or postpone holiday travel to accommodate loved ones in their care.

3. Start new traditions

Instead of focusing on losses and what you and/or your loved ones aren't able to do this year, try doing something new. If your care recipient has trouble getting around, drive through a holiday light display or watch a holiday concert on TV. If you can't make it to a holiday gathering, have a video chat. Are your loved ones

unable to participate in decorating this year? Invite a friend over to help, with your loved ones nearby to watch and cheer you on. Start a home holiday movie night tradition — or watch old home movies so everyone can participate. For more on caregiving, visit AARP's Care Guides.

4. Adjust meals

Food is a big part of many holidays, so it's especially difficult to think about changing mealtime traditions. But meals also require a lot of time, money and coordination. Over many years of caregiving, I found doing holiday baking and meals so exhausting that I couldn't even enjoy them. So rather than canceling holiday meals entirely, I've learned to make adjustments like these:

- Simplify the menu. Try fewer side dishes or one dessert instead of three.
- Split up the grocery shopping and cooking among other family members and guests. There's nothing wrong with a potluck.
- Pay someone to cook meals at your house ahead of time or on the holiday.
- Purchase all or part of meals at a local grocery store or restaurant — either fully cooked or ready for you to cook at home.
- Eat at someone else's home, or at a restaurant.

5. Approach gift-giving more efficiently

Gift-giving is a part of many traditions, but it can be costly and time-consuming. Try shopping online (many online stores will also gift-wrap). You might ask a friend or relative to do your shopping and wrapping for you. You can always fall back on gift cards, too. Family caregivers are often financially stressed, so it might be necessary to lower your gift-giving budget this year and scale back the number of presents. Try giving the gift of time or attention, like scheduling outings or helping with a project. If your family is large, draw names and exchange with just one person. Have a regifting exchange, sharing items you already have. Order a photo gift — like a photo mug, pillow or calendar — or write a meaningful letter that can be enjoyed throughout the year.

6. Anticipate holiday hot buttons

Are there holiday activities or toxic relatives that trigger stress or unhappy memories? Perhaps feelings of grief or loss overcome you at certain times of day. Do unhelpful relatives arrive for the holidays and criticize your caregiving? Maybe old family issues inevitably flare up at gatherings. It may be best to limit your

exposure to — or even avoid — certain places, events, conversations or people. If you can't do that, prepare yourself. Minimize the drama; don't try to resolve problems over the holidays. Instead, try short encounters and develop quick exit strategies. Mentally put yourself in a protective bubble, letting negative energy bounce off without hurting, annoying or distressing you.

7. Mind your mindset

Negative thinking actually activates your body's stress response, so steer your mind to the positives when you start down that slippery slope. Try to stay mindful, concentrating on the present moment. Think about what you can accomplish instead of what isn't getting done; celebrate what your loved ones can do, rather than dwelling on what they can no longer participate in; revel in the holiday joys you experience instead of focusing on those you bypass; appreciate the help you are receiving rather than resenting those who aren't supportive.

8. Keep self-care at the top of the list

As caregivers, we give and give and give, and during the holidays we give even more. All that giving can leave you running on empty, with high stress levels or even full-on burnout. Be aware of emotional ups and downs, fatigue, foggy thinking, inability to sit still or the opposite — feeling frozen and unable to get anything done. These red flags have to be dealt with, but when we're busy it's easy to let self-care slip — just when we need it most. Find ways to fill your tank. Get plenty of sleep. Walk with loved ones in a decorated shopping mall, dance to holiday music, stretch or do jumping jacks while watching holiday movies. Enjoy holiday goodies, but be aware that too many sugary treats can make your energy crash later. Be aware of unhealthy coping skills, like overeating or drinking too much. Get outside for some mood-elevating vitamin D from sunlight, or consider therapeutic lighting if you suffer from Seasonal Affective Disorder. Relax with some holiday-scented aromatherapy to soothe and boost your mood.

9. Connect with other caregivers

Other caregivers are feeling many of the same emotions you are, even when others don't understand. Connect to share your feelings and get tips for holiday survival. If it's difficult to get to a caregiver support group due to holiday business or weather, try online message boards or social media groups.

10. Ask for help

Even if you don't normally do so, the holidays are a great time to get some extra help — even a few hours can be a huge relief. Family and friends can help with holiday preparations. A personal assistant or concierge can complete items on your holiday to-do list or handle personal things like organizing mail or running errands. Get someone to clean the house or catch up on laundry. Ask family and friends to help with direct care for your loved ones, or try community resources like adult day care centers, in-home or facility-based respite care, or paid home health aides/caregivers.

Remember, you'll be happier if you can go with the flow and expect that there will be some delays, a crisis or two and maybe some disappointments. Our family spent Christmas in the hospital with my dad one year when he was sick. We made the most of it with decorations and music and festive hats and antlers. The hospital prepared a darn good holiday meal for us, too. The bottom line is that this time is precious. Savor the moments with your loved ones and make good memories you can cherish forever.

The Registry at FLIC

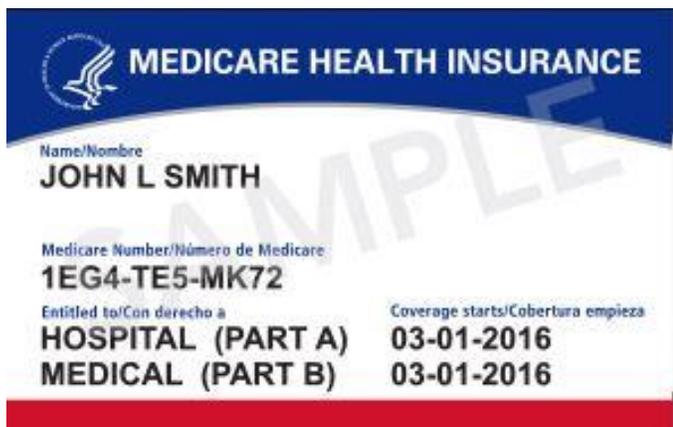


The Registry is a compiled list of private pay aides who have been screened through a face to face interview with the Registry Coordinator at FLIC. References are provided and verified to make sure the aide has the necessary skills and compassion that are important for someone to have when taking care of people in their homes. The Registry also contains a list of skilled nurses varying from pediatrics to palliative care.

For more information **contact Teri Reinemann at 272-2433.**

The Registry program is made possible through funding from the Tompkins County Office for the Aging and the New York State Office for the Aging.

NEWS AND NOTES



Deadline Upcoming! Medicare Open Enrollment

Medicare Open Enrollment ends on December 7th. There is not much time left to make any changes to how you receive your Medicare. Any changes you make will be effective January 1st. Contact the Office for the Aging 274-5482 or Lifelong 273-1511 to make an appointment with a certified HIICAP counselor.

Register now for the final Fall Caregiver Workshop!

The Alzheimer's Association is presenting an education workshop on understanding and responding to dementia-related behavior.

When: December 6th, 2018 from 12:00 - 1:30.

Where: The Conference Room at the Tompkins County Office for the Aging
214 W. Martin Luther King Jr. / State St. Ithaca, NY 14850

Behavior is a powerful form of communication and is one of the primary ways for people with dementia to communicate their needs and feelings as the ability to use language is lost. However, some behaviors can present real challenges for caregivers to manage. Join us to learn to decode behavioral messages, identify common behavior triggers, and learn strategies to help intervene with some of the most common behavioral challenges of Alzheimer's disease.

If you'd like to register for this workshop, please contact Caryn Bullis at the Office for the Aging at 607-274-5450 or by email cbullis@tompkins-co.org.

Last Chance to Attend Stay Steady Tompkins!

The Final Stay Steady Tompkins County Event for the Fall Season will take place on **Thursday, December 13th at the YMCA 50 Graham Rd., 9:30am to 12:30pm)** and you can plan to:

- Come speak with experts in Geriatric Physical Therapy (under the direction of Geriatric-Certified Physical Therapist, Anne Reilly and team).
- Pick up resources about Physical Therapy and exercise programs that improve strength, balance, mobility and reduce fall risk.
- Take part in a brief Fall Risk screening that includes balance and mobility screen.
- Find out if you are at low, moderate or high risk for falling and what you can do to lower your risk for falling.
- Review your medication list with a pharmacist or nurse and ask questions about medications.
- Pick up resources and information about vision health and fall risk.
- Speak with an occupational therapist about home safety and adaptive devices and equipment.
- Learn about many additional resources (available through the Tompkins County Office for the Aging and the Tompkins County Health Department) to make your home safer. Get information about a free home assessment and home modification options.

Remember, you have the power to prevent falls. Educate yourself and take action now.

For more information you can email Carolyn Beyers at cbeyers@hsctc.org or call 607-273-8686.

Contributions Welcome!

If you can afford a contribution to the Caregivers' Resource Center, it will help support this newsletter, our lending library, and other caregiver services. You can make a contribution in person, or by mail at:

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

Please don't feel pressured to contribute financially if you are not able to do so.

Thank you,
Rodney Maine, Caregiver Coordinator
607-274-5491 or rmaine@tomkins-co.org

Reminder!!! You can always contact the Office for the Aging for information and referral on Caregiver and Long Term Care services at 274-5482.

If you would like to be taken off our mailing list, or if you would like to be taken off our mailing list but added to our Email list, please contact us!

Thank you!!!

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

Rodney Maine, CRC Coordinator and Newsletter Editor

Telephone: 607-274-5491

Email: rmaine@tom-pkins-co.org



Caryn Bullis, Project CARE Coordinator and Newsletter Editor

Telephone: 607-274-5450

Email: cbullis@tom-pkins-co.org

Websites of Interest to Family Caregivers:

Tompkins County Office for the Aging: www.tom-pkinscountyny.gov/cofa

- *Click on "Local Resources for Older Adults" to access our Tom-pkins County Resource guides.*

Family Caregiver Alliance: www.caregiver.org

CaringBridge: www.caringbridge.org

Caregiver Action Network: www.caregiveraction.org

AARP Caregiver Resource Center: www.aarp.org/home-family/caregiving

Next Step in Care: www.nextstepincare.org

Note that articles marked "reprinted with permission" may not be further reproduced, except for private use, without permission of the original publisher. Other material in this newsletter may be freely copied with proper credit given to its original source.

This newsletter is made possible in part by a grant from the NYS Office for the Aging