



TOMPKINS COUNTY  
OFFICE FOR THE AGING

*Aging Better, Together*



*Winter 2019*

*Vol. 36*

## ***In Support of Caregivers***

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

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## **Local Caregiver Support Services**

Caregiver's Resource Center & Project Care Services

*Tompkins County Office for the Aging*

Rodney Maine 274-5491

Dawn Sprague 274-5499

*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 Dawn 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** 

**New Caregiver Support Group beginning in January!**

**1st Tuesday of the Month at 11** at the Tompkins County Office for the Aging, 214 W. Martin Luther King Jr. / State St., Ithaca. To register or for more information call 274-5491.

**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

1<sup>st</sup> 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.

## **Funding for Family Caregiver Respite**

The Tompkins County Office for the Aging has a limited amount of funding to help family caregivers afford to hire substitute care that enables them to take a break from caregiving, usually a few hours a week. We have some uncommitted funds available for November and December of this year if you know a family caregiver who might want to take advantage of this opportunity.

### **Eligibility:**

**Title III E Respite:** This is federal funding that pays for respite service for family caregivers who are caring for an older adult (60 or older) who needs assistance with 2 or more ADL's (dressing, bathing, incontinence, transferring, toileting, eating) **OR** needs substantial supervision due to cognitive impairment (e.g., Alzheimer's or other dementia).

**Alzheimer's Respite Scholarships:** This is New York State funding granted to Tompkins County through the CNY Alzheimer's Association. This funding pays for respite service (at home or in a licensed care facility) to give a break to family caregivers of persons diagnosed with Alzheimer's or other dementia.

Although neither program is means-tested, we do try to target these funds to those who find it difficult to privately hire enough substitute care.

### **To Apply or Inquire:**

Please encourage family caregivers to contact Joanne Wilcox or Terry McCann at Tompkins County Adult and Long Term Care Services (607-274-5278). This needs to be done ASAP to set up service in November or December, with the possibility of the service continuing in the new year.

Because of the overall shortage of aides, or if clients prefer it, they may be able to use this funding to privately hire friends or relatives or aides listed with the Finger Lakes Independence Center (FLIC) through FLIC's Consumer Directed Personal Assistance Program (CDPAP)."

# Time Off for Family Caregivers Can Be Invaluable

## A break from caregiving duties is a necessity, not a luxury

by Amanda Singleton, AARP, September 11, 2019

Ask a round-the-clock family caregiver how many breaks she takes, and the answer is usually “not many” or, even worse, “none.” We know that time away from our caregiving roles is absolutely necessary. And yet it's easier said than done.

In the absence of a strong team of co-caregivers, respite care is invaluable. Respite care is temporary substitute assistance that allows family caregivers to step away from their duties for a bit. They can be relieved for a few hours, a full day or overnight, or a stint of days or weeks. Despite the relief, many caregivers may face barriers or personal resistance to using this all too important resource.

It took a total physical burnout for me to accept respite help for my mother. She was physically fragile, recovering from brain surgery and intensive chemotherapy and radiation. I wouldn't, and couldn't, leave her. My fear of her having a medical complication or even passing away in my absence kept my thoughts rooted in the mind-set that no one can do what I do. The reality was that calling in respite care helped me do even better.

A cobbled-together network of hospice aides, a home health agency and a private caregiver gave me more time to manage my mom's medical plan and day-to-day household needs, my job and the opportunity to step away from the grind to see my husband and get a bit more rest. Without exaggeration, respite care spared me a mental breakdown.

Did I learn my lesson the first time? Not at all!

Recently, my husband was physically incapacitated — 100 percent unable to walk, stand or even sit up. He was sent home from the hospital with the instructions: “Do not try to get out of bed for at least a month, probably more.” Suddenly, we were down a set of extremely necessary hands in our house. We had a toddler, and I had just opened a law firm.

Again, thrust unexpectedly into a 24-hour caregiving role, I went about it with that same mind-set. I can handle all of this, I thought. No one can do what I do.

That is, until my back went out and I needed to seek my own medical attention. By literally crawling to my phone, I texted a friend and said, “I'm going to need some help.” And again, respite caregivers saved my sanity and made the following months manageable.

As a nation of caregivers, we are reckoning with the fact that we can't devote ourselves completely to caregiving and expect to maintain our lives outside of it. Jobs, personal relationships, social and community connections, financial security, our physical and mental health, and so much more suffer. And the headlines are screaming: We can't make this work without more support.

Our lawmakers are beginning to listen. Movement is happening in our state and federal governments to continue respite care programs and grow them for the future. In the meantime, until the call for better support is answered, here are ways to prepare yourself to tap into respite care if the need arises:

### **Create a game plan**

Plan for respite care, mentally, emotionally and financially: We do not know when or how caregiving will become a part of our life. Yet it is almost certain that it will someday.

Considering that we, or our loved one, will have to be left in another's care can be painful to contemplate. So can the thought that you will not receive enough help from family members who could pitch in to provide respite.

And the cost cannot be ignored. Respite care is expensive — a home health aide is estimated to cost \$4,195 a month.

Advanced discussions with family members about division of caregiving responsibilities and the cost of respite care may limit future conflict and confusion. Attorneys, insurance agents, counselors or financial planners can assist you with budgeting and moving past emotional barriers to using it.

### **Be specific when asking for and giving help**

If you are not the caregiving lead, offer to assist whenever possible.

“Tell me if there's anything I can do!” is the cheery but not specific offer caregivers sometimes hear.

Instead try: “I will come over tomorrow and be with your loved one so you can take a break.” (Understand that medical needs may exist, but even a half an hour to take a walk or a drive is a blessed opportunity for a caregiver.)

Also, consider setting up a time-sharing cooperative or volunteer-based group in your community or a faith-based organization if one does not exist.

### **Research your options**

Know the options for respite care and ways payment can be covered:

- **Look into your state's respite coalitions** and life-span respite programs.
- **Go through your area agency on aging** and eldercare locator to see nearby options.
- **Learn about private and public benefit** possibilities and estimated costs.

You or your loved one may qualify for low- to no-cost programs. Your employer may even offer respite care as part of your employee assistance program or benefits package.

### **Continue to evolve care plans**

Use some of your available respite time to call family or care team meetings and to adapt your plan of action. What we know about caregiving is that needs are subject to change. Conditions may improve or deteriorate over time, such as in the case of Alzheimer's disease in which 24-hour-a-day care should be anticipated for the more severe stages. Although we can't predict all possible outcomes, we can take some of our needed break time to help us plan. The benefits of respite care can't be overstated. Overcoming resistance to its use and obstacles to its availability may be difficult.



# 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.**



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Are you concerned about the safety of a family member or a friend? Are you, or someone you know, at risk for falling in their home? Tompkins County Office for the Aging can help!

We contract with Doyle Medical Monitoring to provide Personal Emergency Response Systems (PERS) to residents of Tompkins County. Standard pricing starts at \$25 a month and there is no installation, cancellation, or service call fee. When you get a PERS through our office, an Outreach Worker will visit your home, install and test the device, and explain how it works. With our Personal Emergency Response Systems, you will receive personalized in-home service, peace of mind, services and connections from a local agency, and 24/7 monitoring service. Call the Office for the Aging today at 607-274-5482 to speak with an Outreach Worker about our devices!





# Caregiving During the Holidays: Have a Realistic & Positive Approach

Carol Bradley Bursack, Minding Our Elders

There's an image of holiday perfection that our culture encourages. Starting with Thanksgiving, we are inundated with images of families happily enjoying each other's company during a holiday meal. Most of us have memories from our childhood that feed this desire for Norman Rockwell-esque celebrations. Even those who didn't have these picture-perfect experiences growing up often strive to create them with their own families.

However, few of us can measure up to the fantasy—caregivers least of all. The vast majority of advertisements, music and blockbuster movies sugarcoat the holidays and shirk the reality that most of us face. These images feed expectations that are impossible to meet.

Today's "average" family is vastly different from those of the 1940s, 1950s and 1960s. These days, our families are often composed of many generations, relations, races and creeds. For family caregivers, elders' varying degrees of health add to the complexities of bringing everyone together for the holidays.

None of these factors stop families from celebrating, though, and they shouldn't. It's just that we tend to carry memories of holidays past close to our hearts. We place a lot of pressure on ourselves to meet or exceed these high expectations, especially for the enjoyment of our youngsters and elders. If we don't feel we've succeeded, we end up feeling guilty. In many caregivers' minds, failing to meet expectations is failing, period. It's time to turn this mindset around.

## **One Caregiver's Holiday Story:**

My kids were fortunate to have their grandparents nearby as they grew up. Along with creating cherished memories with Grandma and Grandpa, however, they also witnessed their elders' failing health. They remember dividing the holidays between visiting loved ones at the nursing home and celebrating at our house with those family members who could still manage to come over. Unfortunately, I'm sure they also remember my frantic struggle to meet the expectations of every generation with only limited success.

Each year after Thanksgiving, I would make my rounds, decorating each elder's apartment or nursing home room, planning how we would split our time between the visits, and striving to meet everyone's needs. The guilt over taking so much time from my kids ate at me. The guilt over my mother not having the Christmas celebration she so coveted ate at me. My mother-in-law did not seem to care, yet I knew that deep down underneath the dementia, she did. The frustration of trying to "celebrate" the

holidays when my dad no longer knew what we were trying to do made me want to throw in the towel. Yet, to ignore or minimize this time of year seemed all wrong. Onward I marched, trying to make the holidays sing for people who couldn't hear.

The squeeze of generations and the countless needs of each leave little time for caregivers to think of their own needs. Prioritizing our own health and enjoyment winds up feeling like just another task, so we knock it to the bottom of the to-do list, and keep on doing for everyone else.

But it takes energy to plaster on a smile and say "Happy Holidays," as people in the grocery store greet you. It takes energy to decorate a loved one's home, bake cookies, attend holiday performances, shop and wrap presents—all with a smile, of course. Eventually, you sit back and realize you don't really feel like smiling at all. In spite of all your selfless effort, each person still did not get enough of your time. Everyone feels shortchanged, including you.

All of that energy directed toward creating a perfect holiday didn't produce the perfect results for everyone. In your mind, you failed, and the guilt is all-consuming. You can carry on the tradition this year and run yourself ragged all winter, trying to make a holiday miracle happen, or you can drop the perfect fantasy and lose the caregiver guilt.

## 5 Steps for Avoiding Caregiver Guilt Over the Holidays

1. **Reset the computer in your head.** That's right. Wipe out the hard drive that carries holiday memories of the past. The perfection you remember is likely skewed, anyway. The circumstances back then were very different, and it's time to celebrate the holidays in a new way that fits your life as it is right now.
2. **Watch a silly holiday movie.** I'm serious. Find a funny, imperfect and touching holiday movie, like "Elf" or "National Lampoon's Christmas Vacation," and make it a part of your celebration each year. Years ago, my youngest son and I started watching "Merry Christmas, Mr. Bean" each Thanksgiving holiday. The tradition began after we experienced deaths in the family over the holidays two years in a row. After the second grieving holiday season, I still remember my son saying to me, "I hope we don't have a funeral this Christmas." We didn't. However, we did again the following Christmas. Throughout our funeral-strewn holidays, we watched "Mr. Bean" at least once. Somehow this character, who lives in his own little world, is able to create his own happiness. When he tries to live life like other people, he fails. But when he is true to himself, he is happy. There's an important lesson there.
3. **Be thankful.** In most cases, before we can be thankful, we have to come to accept where we are in life. Often there are circumstances that we would love to change and many that we never anticipated, but it's where we are. If we accept it, then we can work our way toward expressing some gratitude. Maybe this

gratitude is only that we are learning and growing from our hardships and setbacks. But even slight feelings of appreciation can help improve our attitude and help us see what is really important.

4. **Communicate with your loved ones.** Even small children can understand, if they are told in a loving way, that your time is short or you have to cut corners because Grandma and other family members rely on you, too. Communicate the same thing to the elder(s) in your care. Helping the entire family understand that each person's desires are important but that you have a lot on your plate can help keep their expectations more realistic. You'd be surprised how much a senior, even one who has dementia, can understand. The holidays are about giving and sharing out of love. Having this conversation with the family may even inspire them to lend a hand or cause your elders to encourage you to spend quality time with your kids.

**Simplify your plans and enjoy what truly matters.** Forgive yourself for the scant decorations, the online shopping and the skipped Christmas cards. In fact, congratulate yourself! Remind yourself that your health and sanity are a gift to your loved ones. By skimping on some of the frills, they will have more quality time with you. And that is far, far more important than a Norman Rockwell Christmas.



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## Project CARE

Project CARE is a **friendly visitor program** in Tompkins County for Seniors age 60 and over. Project CARE provides companionship to Seniors by having a volunteer make a weekly visit. Project CARE can be a great comfort to Seniors by providing in-home support and companionship, especially to frail or homebound older adults, those that are socially isolated, as well as family caregivers.

### Weekly visiting:

Many Seniors in our community greatly benefit from a weekly visit. Visits provide a caring bond, especially to those who are socially isolated. Volunteers can provide conversation, support, organize calendars/paperwork, play games, go for a walk, read to their Senior, polish nails, do a puzzle together, and much more.

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*If you are interested in having a Project CARE friendly visitor please contact Dawn Sprague at NY Connects Tompkins County Office for the Aging by phone @ (607)274-5499 or email @ [dsprague@tompkins-co.org](mailto:dsprague@tompkins-co.org) to discuss this opportunity further.*

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# 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

## Home Energy Assistance Program (HEAP)

**The regular HEAP season will open November 12, 2019 and is anticipated to close March 16, 2020.**

The Home Energy Assistance Program (HEAP) provides assistance with fuel and utility expenses for income-eligible homeowners and renters. The HEAP program may also be able to help with furnace repair or replacement. The Tompkins County Office for the Aging processes HEAP applications for persons over age 60, and for those who receive SSI, or SSD, and do not receive Food Stamps. The current income eligibility levels for HEAP in 2019-2020 are as follows:

<b>Household Size</b>	<b>Maximum Gross Monthly Income</b>
<b>1</b>	<b>\$2,494</b>
<b>2</b>	<b>\$3,262</b>
<b>3</b>	<b>\$4,030</b>

If you think you may be eligible for HEAP, contact the Tompkins County Office for the Aging (607) 274-5482 for more information.

***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**

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**Email:** [dsprague@tompkins-co.org](mailto:dsprague@tompkins-co.org)



### **Websites of Interest to Family Caregivers:**

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

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

**Family Caregiver Alliance:** [www.caregiver.org](http://www.caregiver.org)

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

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

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

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

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