



Winter 2020 Vol. 39

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.

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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

There may be changes to this program due to COVID-19

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.



Most Support Groups are still meeting virtually.

Caregiver Support Group at Brookdale

Last Thursday of every month at 5:30pm at Brookdale, 103 Bundy Rd. Ithaca. Light meal provided. Facilitated by Bruce Rogers. For more information contact Lisa: 342-6050.

Family Caregiver Support Group

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

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.

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 if you know a family caregiver who might want to take advantage of this opportunity.

Eligibility:

Title IIIE 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).** Due to the overall shortage of aides, or if clients prefer it, they may 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)."

What Vaccines are Recommended for You

Immunizations are not just for children. Protection from some childhood vaccines can wear off over time. You may also be at risk for vaccine-preventable disease due to your age, job, lifestyle, travel, or health conditions.

All adults need immunizations to help them prevent getting and spreading serious diseases that could result in poor health, missed work, medical bills, and not being able to care for family.

- All adults need a <u>seasonal flu (influenza)</u> vaccine every year. Flu vaccine is especially important for people with chronic health conditions, pregnant women, and older adults.
- Every adult should get the <u>Tdap</u> vaccine once if they did not receive it as an adolescent to protect against pertussis (whooping cough), and then a <u>Td</u> (tetanus, diphtheria) booster shot every 10 years. In addition, women should get the Tdap vaccine each time they are pregnant, preferably at 27 through 36 weeks.

Almost 1 out of every 3 people in the United States will develop shingles in their lifetime. Your risk of shingles increases as you grow older. Additionally, over 60 percent of seasonal flu-related hospitalizations occur in people 65 years and older. As we get older, our immune systems tend to weaken over time, putting us at higher risk for certain diseases. This is why, in addition to seasonal flu (influenza) vaccine and Td or Tdap vaccine (tetanus, diphtheria, and pertussis), you should also get:

- Shingles vaccine, which protects against shingles and the complications from the disease (recommended for healthy adults 50 years and older)
- Pneumococcal polysaccharide vaccine (PPSV23), which protects against serious pneumococcal disease, including meningitis and bloodstream infections (recommended for all adults 65 years or older, and for adults younger than 65 years who have certain health conditions)

 Pneumococcal conjugate vaccine (PCV13), which protects against serious pneumococcal disease and pneumonia (recommended for all adults with a condition that weakens the immune system, cerebrospinal fluid leak, or cochlear implant)

Adults 65 years or older who have never received a dose of PCV13 and do not have one of the conditions described above may also discuss vaccination with their vaccine provider to decide if PCV13 is appropriate for them.

Talk with your doctor or other healthcare professional to find out which vaccines are recommended for you at your next medical appointment.

This information was gathered from the CDC Website.

View the Full CDC Webpage at https://www.cdc.gov/vaccines/adults/rec-vac/index.html

7 Ways Caregivers Can Create That Holiday Feeling Amid the Pandemic Adapt old traditions, or start new ones, to help loved ones adjust

by Amy Goyer, AARP, November 19, 2020

For most of us, the holidays will be different this year. For family caregivers, there are extra challenges as we struggle to make the season feel special for loved ones who may be isolated and grieving the loss of the usual traditions.

In a recent survey of caregivers by Care.com, 85 percent of respondents named the holidays as the primary time of year when their family comes together with an older loved one. More than 2 in 5 say they will not be able to see their care recipient in person this holiday season.

Many care recipients may feel depressed or abandoned, or have difficulty understanding the changes due to cognitive issues. That makes it all the more important for us to make the holidays as full of meaning and connection as possible for our loved ones, within the limits of safety precautions.

The good news is, there's no need to cancel the holidays this year — just make them unique! There are lots of ways to help ensure the 2020 holidays still bring comfort and joy.

Easing the adjustment

As caregivers, we need to balance our loved ones' mental and physical health, keeping them safe while also keeping them connected. Nearly half of family caregivers say the pandemic has had a negative effect on their care recipient's mental health, and three-quarters worry about the risk of COVID-19 exposure at holiday get-togethers, according to a new AARP report on how COVID-19 is affecting holiday plans.

While 62 percent of caregivers plan to get together with family at some point during the season, many of those gatherings will be smaller, shorter and devoid of physical contact, the AARP survey found.

"I am OK with a year off from hosting massive gatherings," says Renee Riley, a longtime caregiver for multiple family members in Columbus, Ohio, "but I worry about family members who live alone and face such loneliness."

Start by acknowledging that things are different, and validate whatever your loved ones are feeling, whether you agree or not. It's OK for them, and you, to feel sad, angry, disappointed or even relieved that some holiday traditions will be canceled or amended. Reassure loved ones that their health and safety are everyone's top priority.

But remember, too, that holiday activities help bring us out of our everyday lives, lifting moods and sparking good memories and joy. So, try to focus this year on the holiday things you can and will do rather than those you can't or won't do.

Making the season feel special

It's a complicated challenge. "Regardless of how much they 'understand,' traditions held for years will be broken this year," says Roberto Quinones of Tysons Corner, Virginia, a <u>long-distance caregiver</u> for his parents, who live in New York City. "How can we keep the positive outlook with remote parents we're not able to visit?"

Make it your goal to create shared experiences — for most people, that's what makes the holidays the holidays. Here are some tips on how to adapt holiday traditions to make them uniquely special this year.

1. Make frequent contact

If you generally call your loved one once a week, up your game. If your family gatherings were centered around the few days immediately surrounding a holiday, try spreading out activities over the coming weeks instead. These steps are especially important if your loved ones live alone or in long-term care facilities.

Marianne Parker of Quincy, Illinois, saves holiday greeting cards she receives, covers the signature with a sticker, signs the names of family and friends, and sends them to her brother, who has dementia and lives in a memory care facility.

"I'll have the facility give him one or two each day in December as though he received them in the mail," Parker says. "I hope getting a card each day may spark and keep alive a holiday feeling for him, and I'm organizing friends to go Christmas caroling at the facility, too."

2. Avoid all-or-nothing thinking

Feeling like holiday activities aren't worth doing if you can't do it all can leave you and your loved ones feeling empty. Some overwhelmed caregivers feel a bit relieved that certain holiday activities are canceled this year; others will adapt and focus on what is easiest, like holiday table linens to create a festive feeling.

You may even want to go all out more than ever for some activities — it's all OK. Just try to anticipate how your loved ones will feel and talk over plans with them if possible. If they balk at adapting old traditions for current circumstances, take a new approach and surprise them.

3. Focus on activities that mean the most

There is comfort in the familiarity of holiday traditions. Ask loved ones what seasonal rituals are most important and fulfilling for them, and get creative about ways to adapt them:

- Is the annual cookie baking a highlight? Bake and send a batch to your loved one, or make them simultaneously while on a video call.
- Are holiday music performances and religious services most meaningful? Find concerts and services on TV or online and watch together.
- Are certain vintage decorations a must, but you can't get to a loved one's home to get them out of the attic? Try to find something similar (you'd be surprised what you can find in online auctions), or buy a new item and ship it for them to enjoy.
- Is the traditional family green beans recipe what makes it a holiday meal for them?
 Make the dish, get dry ice and ship it!

4. Create a mood with holiday decorations

I used to bring my grandmother a little potted Christmas tree when she could no longer put up a large one, and her eyes sparkled each time. Caregiver Deb Kelsey-Davis of Downers Grove, Illinois, says it's holiday lights that give her parents a lift.

"I put my parents' lights and tree up," she says. "It makes such a big difference with Dad and Mom ... gives them such joy! We had a good time, too, reminiscing about Christmases past."

She's not alone: Just over half of U.S. adults plan to put extra oomph into holiday decorating to brighten up the end of this tough year, according to a survey by Porch, a company that provides customer-management solutions for moving and home maintenance professionals.

If you are avoiding indoor visits, ask family and friends to help with outdoor decorations your loved ones can enjoy from their windows. If they live in facilities, ask to put decorations outside their window for a daily reminder of your presence. Share videos and photos of your holiday decorations, or those you see in your neighborhood or online.

If loved ones are decorating in their homes, you can cheer each other on and chat while you work. Try sending ready-to-display items like a small decorated pumpkin, turkey toy, tree, menorah or other symbol of the holidays.

Decorations can give caregivers a boost as well. I'm getting mine out early this year because I need a little cheer, being 2,000 miles away from my sister as she gets ready for a major surgery.

5. Take your traditions virtual

Virtual connections can go beyond a short conversation. Do you sing carols, bake, create crafts, or watch It's a Wonderful Life every year like my family does? We're doing these things from a distance thanks to video chat apps like FaceTime, Zoom and Skype.

For example, we choose a movie and queue it up on our DVR or streaming device. Then we call each other on FaceTime, hit play at the same time and watch in unison, unmuting our phones to share laughs, tears or comments. It's the next best thing to being together!

Or you might set up a phone or tablet on a tripod so you can see each other and bake, create crafts, feast, play charades or trivia, or engage in other holiday traditions. Play digital games together, online or via apps. Record and save as visual keepsakes loved ones can return to, as you might make videos of traditional holiday get-togethers.

6. Shop online together

Help loved ones do their holiday shopping online, together or from a distance. Remember the old Sears catalog Wish Book? Create your own version by downloading or printing photos of items they might like, creating a document or notebook, and sending it for them to peruse.

7. Start new traditions

It can be helpful to focus forward instead of on the past. Make this a year to create new holiday rituals. Perhaps you could:

- build a holiday bonfire
- make homemade gifts
- meet for a walk outside
- cook the same recipes from a distance and compare
- read to kids or grandkids via video calls
- call each other while you have your first holiday morning cup of coffee

Those old family traditions had to start somewhere, right? Some of your holiday adaptations this year will likely become traditions!

Daunting as it might seem to make the holidays memorable this year for something other than their difference, in future years we may look back and marvel at how creative we were.

Amy Goyer is AARP's family and caregiving expert and author of Juggling Life, Work and Caregiving. Connect with Amy on amygoyer.com, Facebook, Twitter, in AARP's Online Community and in the AARP Facebook Family Caregivers Group.

Personal Emergency Response Systems



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!



Changing How We Provide Care: Lessons Learned From the Pandemic

Coronavirus has put a spotlight on the new challenges of caregiving

by Amanda Singleton, AARP, October 27, 2020

It's hard to believe until it happens to you, but caregiving and crisis can strike at any time. The COVID-19 outbreak has forced all of us to face that possibility. Since the beginning of the year, many Americans have become caregivers for the first time. And half of those have become caregivers because of COVID-19. People who were already caregivers have been affected too. Nearly half of family caregivers are reporting that their caregiving responsibilities have increased because of the virus.

I became a caregiver over the summer (not because of the coronavirus). It's not my first experience caregiving for a loved one but doing so in the midst of a pandemic makes it feel brand new. I am not permitted to accompany my care partner inside medical appointments. In-home help is not readily available or easy to arrange. It's been frustrating and time-consuming to provide care in 2020.

Even for experienced caregivers, there's been a forced adaptation. By today's estimates, we can expect the virus to be a part of our lives for years to come. This means present and prospective caregivers need to account for the virus in their medical, legal and financial planning.

Preparing for the Unpredictable

A caregiver's biggest asset is time. Reports indicate that caregivers are spending an additional nine hours a week (a full workday!) on caregiving activities in 2020. And there are mental and physical tolls that are increasing stress significantly. Getting organized and preparing for caregiving events will give the gifts of time and reduced stress when duty calls.

Life care planning documents reduce caregiver strain

Americans don't like to talk about mortality. When asked, most people will agree that end-of-life planning is important, but less than 40 percent of people sit down to formalize their planning in writing. Since the outbreak, we've all been reckoning with the possibility of contracting a virus that can wreak havoc on long-term health and has taken the lives of many older Americans. If there's ever a time to talk about planning for an unexpected illness, this is it.

So, talk to your loved ones. The holidays are around the corner and while we may not be gathering as we have in the past, we can still reach out to family and friends. Take

the opportunity to discuss life care planning and assist each other in making and sharing your legal and medical documents. Whether there is a family coronavirus crisis or some other unexpected event, you will be relieved that you've taken these steps.

Get your home — and yourself — ready

I've definitely lost sleep thinking about how my household will function if one of us contracts the virus. While I've had to make disaster plans as a caregiver in the past (living in hurricane-prone Florida and taking care of a parent with cancer and high-level medical needs meant having an evacuation plan and a stockpile of essential items), I avoided thinking about what would happen if I got sick. As a cancer caregiver, I got a flu shot and hoped for the best. As a caregiver and parent today, considering how I'll handle childcare and running our household (not to mention my business!) if I must self-quarantine because someone in my immediate family contracts the virus is an unavoidable reality.

AARP and the CDC have recommendations and checklists to assist caregivers in their preparations. Thinking about ways to limit contact or separate from a vulnerable family member is easier to do in advance than on the fly. Knowing what respite care options are available to you can save time and reduce caregiver burnout. Learning your options and having a backup plan for yourself and household members to recover from the virus and help quell its spread is a new — and necessary — part of caregiver disaster planning.

Embrace alternative means to receive medical care

Telehealth (medical care provided remotely, by phone or videoconference) has been increasingly used this year. It keeps caregivers from having to expose their care partner to other, possibly sick people at an office visit. Encourage your family and friends to embrace it and share tips and tools to make the most of telehealth services.

If an in-office visit is a necessity, caregivers must do their research in advance to avoid being surprised on the day of the appointment or when seeking treatment. Learn office and facility policies and procedures in advance to keep the visit as smooth as possible.

Concerns about keeping loved ones safe in facilities are prompting families to reconsider moving into, or remaining in, long-term care. The only way through this is for families to collaborate on alternative options, whether it is aging in place, shared elder care, or another option.

Studies show that 1 in 3 Americans are researching how they would pay for long-term care services if they needed them. Take the reins on this today if you expect that you or your care partner will need medical or nursing care beyond what can be provided at home.

Financial Security

In online searches and support groups, caregivers frequently ask if there is a way to be paid and how they will keep their jobs while juggling at-home responsibilities. It's no wonder this is such a popular topic among caregivers, especially in a time where so many have been furloughed, laid off and terminated.

Be paid to care

Although there are not many ways, it is possible to be paid to provide care for a loved one or friend. If you want to learn what's available to you, consult an elder law attorney in your state. Aside from government and insurance programs, it may be possible for your care partner to pay you and still qualify for their own public benefits.

The fact that this is such a popular topic means that we all have to put paying our caregivers into our financial plans. Can money be set aside in our long-term plans to account for the realistic possibility that a relation or friend will have to care for us? Ultimately, it may be less expensive than paying for help from professionals.

Maintaining employment and receiving caregiver benefits

The job market is uncertain. Feeling the strain, many people are forced out of work or departing on their own. And it's mostly women, who are leaving at four times the rate of men.

While this seems bleak, the coronavirus has prompted a sharp and sudden acceleration in the implementation of family-care benefits in workplaces nationwide. More companies are offering subsidized backup elder- or child-care. And flexible work arrangements are becoming commonplace. It is estimated that three quarters of American corporate workplaces are now offering flexible arrangements, spurred in large part by the pandemic.

These trends all favor the unique work-life juggling act that caregivers experience. If your company isn't offering these benefits or is resistant to them, sharing the research and guides may help create a culture more suited to the needs of caregiving employees today and tomorrow.

Increasing knowledge and access to resources

Historically, caregivers wait until about a year of caregiving to begin researching outside resources that can help them. We cannot afford to wait so long in such tough times.

Caregivers need to know much sooner what assistance exists and how to access it. With laws and policies changing frequently, it is difficult to stay up to speed. This year,

especially, take the time to learn about major consumer protections that have been passed in response to COVID-19. Retirement savings waivers, mortgage relief, utility assistance, tax credits and loan modification laws could keep your family afloat. Knowing where to find free or low-cost advice, like in the resources listed here, can assist in accessibility. Contacting your local Area Agency on Aging and accessing AARP's resource guides may also point you in a good direction.

Caregivers are used to rolling along with changing circumstances. But even the most adaptable people have felt the strain of the COVID-19 pandemic. We must talk more, not less, about our challenges. We have to plan our caregiving lives, share our experiences and knowledge, and advocate for our workplaces and lawmakers to provide much-needed support. For the foreseeable future, increasing our preparedness and maintaining financial and employment security for caregivers will be a bridge over tumultuous waters.

Amanda Singleton is a recipient of CareGiving.com's national Caregiving Visionary Award and serves caregivers across their life span through her law practice. Follow her on Twitter and Facebook.



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.

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 to discuss this opportunity further.

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





The Caregiver Resource Center at the Office for the Aging

We are still providing support to family caregivers remotely.

Powerful Tools for Caregivers Classes—we will be hosting a virtual six-week course in the coming months!

Caregiver Workshops—Previously scheduled workshops with the Alzheimer's Association have been changed to an online format.

Caregiver Support Group—We will be holding a remote caregiver support group and welcome any family caregiver to join us.

Caregiver Library - We loan out books on caregiving. We can mail you a book from our library!

Caregiver Counseling - We are available by phone to help caregivers navigate services available in our community.

For more information about these services please contact the Caregiver Resource Center at the Tompkins County Office for the Aging, we'll be glad to help you!

Phone: 607-274-5491

Email: rmaine@tompkins-co.org

Visit our website for COVID-19 resources: https://tompkinscountyny.gov/cofa/cofa-COVID

Get Your Flu Shot

A yearly flu vaccine is the first and most important step in protecting against flu viruses. If you need information about where to get your flu shot, please call 2-1-1, or visit https://vaccinefinder.org/find-vaccine

Home Energy Assistance Program (HEAP)

The 2020-2021 HEAP Program is Open.

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 2020-2021 are as follows:

Household Size	Maximum Gross Monthly Income
1	\$2,610
_	00.440
2	\$3,413
3	\$4.24 <i>6</i>
3	\$4,216

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

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Editor

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Websites of Interest to Family Caregivers:

Tompkins County Office for the Aging: www.tompkinscountyny.gov/cofa

• Click on "Local Resources for Older Adults" to access our Tompkins 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

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