



TOMPKINS COUNTY
OFFICE FOR THE AGING
Aging Better, Together



Summer 2020
Vol. 38

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 offers 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 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 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)**. Due to 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)."

How Family Caregivers Can Keep Loved Ones Safe as Stay-at-Home Orders Lift

Consider expert guidance and move forward at your own pace

by Barry J. Jacobs, [AARP](#), May 27, 2020

Shirley felt unsettled after ending the call with her adult son, Kyle. He had talked excitedly about their state's announcement that the stay-at-home order had been lifted and that residents could assemble if they adhered to social distancing. He, his wife and their teenage children were eager to take her and his father, Louis, who had moderate dementia, to their favorite restaurant. How soon could they go? he'd asked.

But Shirley had misgivings. She didn't know how to reconcile the TV images she saw nowadays of joyful, mostly mask-free people packing parks and beaches with the online reports she read about nursing home residents, little older than she, dying of COVID-19. She wanted to have fun, too, and couldn't wait to see her grandchildren in person again but wondered if it was truly safe for people like her and Louis to return to normal life. He had diabetes and high blood pressure, as well as his dementia. She had the early stages of COPD, from having been a heavy smoker in her youth. Weren't those the kinds of chronic diseases that doctors said made people more vulnerable to infection? Was the time right to take a chance?

Many Americans are struggling with similar questions. These decisions are more pointed and consequential, however, for family caregivers. They must think about not just their own safety but that of their loved ones, who may no longer have the judgment to choose for themselves. That's a weighty responsibility. What if a caregiver makes the wrong choice? How guilty would she feel if the care recipient became sick and died? Would other family members respond with sympathy or blame?

These are personal decisions with no clear-cut answers. All family caregivers will have to consider the pandemic's spread in their immediate vicinity, their loved ones' specific health conditions, the level of contact they'd consider having with others, and their degree of tolerance for risk. With so much uncertainty about the coronavirus's course in the months

ahead, they will also have to be prepared to change tack according to evolving circumstances. What process should caregivers use to make these difficult decisions? Here are some thoughts.

Start with medical advice

Health care professionals are inherently cautious — “First, do no harm,” they're famously taught — so soliciting their opinions about what's safe and what's not is a good place to start. They don't decide what you should do; you do, based in part on the guidance they provide and the needs you and your care recipient have. But if they know you and your loved one well and give their blessing to venturing out of the house to reunite with family, then it is likely prudent.

Consider available information

Nowadays the airwaves are filled with politicians and public health experts imploring you to do one thing or another to safeguard your health, bolster the economy or support your neighbors. All this should be taken under advisement. You should weigh the information and perspectives they provide as but one factor in your determination of what works best for you and your family. They are not the last word on your situation.

Weigh risks and benefits

There's no great secret to making a list of pros and cons of a course of action and then deciding which side of the ledger is more persuasive to you. It's just that most of us don't go to that much effort usually. But this is too big a decision for you to shoot from the hip. Slow your decision-making down. Deliberate. Sleep on your thoughts. If you are uncomfortable making any changes, then stay put for now.

Use family as a sounding board

Once you have a strong inkling about whether and how you and your loved one will resume activities outside of your home, you may want to confer with close family members to get their feedback. They may have many opinions about what you should do and when, but, again, it is you who will decide. Nevertheless, their agreement to honor your choice will make it easier for you to implement any decision you make — and they won't pressure you further to go out to restaurants unless you're ready.

Reserve the right to change your mind

In all instances, the best caregivers are flexible and creative problem-solvers. During this pandemic it is no different, though the stakes are higher. As the public health situation unfolds, wise caregivers will frequently assess what's going on, plan and adjust as needed and reverse course if necessary. Safety is always paramount — but trusting your own judgment is essential.

Barry J. Jacobs, a clinical psychologist, family therapist and healthcare consultant, is the co-author of Love and Meaning After 50: The 10 Challenges to Great Relationships — and How to Overcome Them and AARP Meditations for Caregivers (Da Capo, 2016).

Residential Care Options: Caregiving Doesn't End When Your Loved One Moves

By Family Caregiver Alliance

After your loved one moves to a facility, what happens? What is your role as a caregiver? How often should you visit? How can you best help your loved one adjust to their new living environment? How do you cope with your feelings about the move? Here are some tips to help you answer these questions and more.

- In the first two to four weeks, visit often. It's important for your loved one to not feel abandoned. Go daily if possible, even several times a day. More frequent visits are more important than longer visits. Together, take strolls around the facility, point out different areas, visit the garden or library. Bring favorite foods as treats.
- Introduce your loved one (and yourself) to the staff. Tell them about his or her life to help them get to know your loved one. Create a poster of your loved one's life and hang it in the room for all to see. This is a way to honor your loved one and who they are as well as who they were, while helping the staff and others to appreciate their unique history.
- When your loved one is settled and comfortable, start visiting every other day, and then every third day, if that feels okay to you. Create a schedule that works for you. Visit during "free time" when there are not other activities going on. Don't stay too long. Visit at different times of the day to see how he or she is doing throughout the day, including meal times.
- If your loved one has dementia, remember that his or her experience of your visit will be the same if you stay twenty minutes or two hours. Find the length of time for your visit that works for you.

- Unless your loved one really likes to go for drives, postpone outings until he or she is adjusted to the new environment. Think about whether the trip is for their sake or yours (to feel you are doing something good or perhaps to reduce guilt?)
- Decorate the space, whether it's a shared room or private. Have familiar objects around such as family pictures, artwork, flowers, plants. Use the wall poster to tell your loved one's story and to give you something to talk about when you visit.
- Attend activities with your loved one to help them get oriented and involved in the community. Play games that he or she used to like, such as cards, dominoes, or Scrabble. Watch television or videos of old movies together. Listen to music they like. Talk about sports. Sit together and hold hands—people in facilities don't get touched much except when someone is "doing" something for them. You might also be experiencing this loss of touch and intimacy.
- Bring old photo albums or go online to visit Facebook pages. Share stories of what other family members are doing.
- If you know someone else has recently visited, remind your loved one that they came. Leave a journal in the room for guests to leave a friendly note and read the notes back to your loved one.
- Visit together with a family member or friend. (And go out for lunch or coffee together afterwards as a treat for yourself!) If the facility and your loved one's condition allow, brief visits with children or small pets can be great diversions.
- Reassure your loved one that he or she is safe, loved, and cared for.
- Understand that the care staff in the facility will not do things exactly the way you do. They will do things differently. But you can provide some of the hands-on care if you want.
- Be clear about your care expectations and be willing to share with the staff what has been successful for you in the past.

- If you have concerns about the care your loved one is getting, speak up. Talk to the director or nurse. Do not just ignore issues until they have become major problems.
 - Create a relationship with staff members who take care of your loved one. Greet them by name, offer praise when they do something especially helpful for your family member.
 - Remember it takes a while to establish trust. Treat everyone with respect.
- Be aware that when a staff who you like and trust leaves, it can be hard for you and your loved one to adjust. Take the time to recognize the loss and plan for how to get to know the new staff.
- If you are still concerned about the quality of care your loved one is getting, contact the long-term care ombudsman in your area (information should be posted at every facility).
- Moving a loved one to an assisted care residence can be emotionally difficult. Grieve. Allow yourself to feel sad, depressed, angry, disappointed, worried, anxious, but also relief, peaceful and calm. You may feel many emotions as a result of this decision. This is a hard transition and these feelings are necessary to start the healing process. But avoid guilt—you are not responsible for your loved one's illness or their need for more care.
- You may experience ambiguous loss—someone is “there but not there.”
- Practice letting go. It's okay for you to have a life outside of caregiving. Your renewed energy will make it easier to visit and you will have more to share. You have a right to enjoy your life. Embrace the transition of your role from a full-time caregiver to a spouse, adult child, or friend.

It takes time to transition to a new living situation. You can help facilitate the process by accepting that you are making the right decision. Given time, most people thrive in the new environment. With activities geared for their level of functioning and people to socialize with, your loved one can feel

more successful and engaged. The key to a successful transition is to see your relative feeling safe and trustful of you and the staff.

Sometimes caregivers worry that their loved one doesn't need or love them any more. This is just confirmation that he or she is in a good place and getting the care that's needed. Congratulate yourself on making a good decision. You are still the most important person in your loved one's life. And you are still part of the care team. You are your loved one's strongest advocate. Caregiving doesn't end, it just changes.

Personal Emergency Response Systems



TOMPKINS COUNTY
OFFICE FOR THE AGING

Aging Better, Together

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!



Have a Nursing Home Complaint? Meet Your Long-Term Care Ombudsman

Every state has one — and many are busier than ever because of the coronavirus

by Emily Paulin, [AARP](#), May 1, 2020

As the coronavirus ravages the country's nursing homes, those with loved ones on the inside are wondering where to go for help with concerns or complaints about a long-term care facility.

The answer may be your nearest long-term care ombudsman. Every state — plus Puerto Rico, Guam and the District of Columbia — has a long-term care ombudsman office that works to promote and protect the rights of residents in nursing homes, assisted living facilities and other residential care communities. The offices work with residents to address problems related to their health, safety and rights. If a resident, family member, representative or staff member is worried about a resident's care, they can file a complaint with the ombudsman's office.

With COVID-19 killing more than 17,000 nursing home residents and staff members and infecting tens of thousands more, the offices are getting more attention.

"We're busy in normal times. This is insane," says Mark Miller, president of the National Association of State Ombudsman Programs and state long-term care (LTC) ombudsman of the District of Columbia, which is part of AARP's Legal Counsel for the Elderly. Questions and complaints related to COVID-19 are skyrocketing, he says: "There's no running from it.... And to be honest, we're concerned."

Before the pandemic closed nursing homes to almost all visitors, ombudsmen were in nursing homes frequently.

"Our bread and butter, what we do every day, is visit facilities, talk and meet with residents, get to know them, build trust and rapport with them, then gather information as to what their concerns are about," says Patricia Hunter, the LTC ombudsman for Washington state. With permission from

the resident to act on a complaint, which can range from subpar food to claims of neglect and abuse, ombudsmen will investigate the issue and work to resolve it. Their services are free of charge and, if desired, confidential.

More than 1,000 paid staff and 6,000 certified volunteers form the Long-Term Care Ombudsman Program, which is funded by the federal Administration on Aging. Established in the 1970s under the Older Americans Act, the program is government-funded but works explicitly for long-term care residents. “We don't have the trappings of big government agencies,” says Hunter. “We have independence, which is critical.”

State offices varies in size, based on the number of facilities, and most are broken into regions, with a designated ombudsman for each. The most recent data on the national program shows they investigated just under 200,000 formal complaints in 2018. They provided information to an additional 400,000 people inquiring about long-term care.

In addressing complaints, “we're always going to try low-level problem solving first,” says Hunter. “That might entail literally just a phone call or email, or it might involve getting everyone together — the resident, their family member, nursing staff, physical therapist, whoever needs to be involved — to implement a plan going forward that is going to support the resident and their needs.”

If that doesn't work, or if a facility refuses to cooperate, or if a complaint is particularly egregious, ombudsmen can refer complaints to higher-level regulatory or enforcement agencies with permission from the resident. Ombudsmen lack enforcement power, but they can refer cases to the state's health department overseeing nursing home licensing, adult protective services, the police or the courts.

Problem-solving in a pandemic

The pandemic is making ombudsmen's jobs much harder. Like families, friends and representatives of senior care residents, they've been barred by the federal government from entering facilities in most cases, to protect residents and staff. Ombudsmen also want to protect themselves — most volunteers for the program are older, putting them at greater risk for COVID-19.

"It's a huge hurdle," says Miller. "Generally, when you do any investigation, you're physically there getting eyes on the situation, looking at records, interviewing staff. Trying to solve the issue telephonically is much more difficult."

Nonetheless, complaints keep coming in and investigations continue. In New York, for example, many families are struggling to reach facilities with questions about their COVID-19 response plans. So ombudsmen there are requiring facilities to fill out questionnaires asking "how they're managing during the crisis, how they're interacting with residents, what activities they're providing, how they're managing meals, how they're managing with" personal protective equipment, says state ombudsman Claudette Royal.

Ombudsmen relay the information back to families, sometimes arranging virtual follow-up meetings between families and facilities, Royal says. In D.C., residents are calling in feeling scared or lonely, Miller says. So ombudsmen are conducting weekly telephone or FaceTime calls with residents, asking a series of questions about their care and facilities' infection-control practices. They're also scheduling window visits with residents.

Washington's office is receiving complaints about facilities refusing to allow hospice services in, Hunter says. "There's a potential violation of rights there," she says, "so we're looking at all the legal options ... and I'm not afraid to use them if I have to."

Advocating for systemic fixes

Beyond handling individual complaints, many ombudsmen advocate at local, state and national levels for systemic improvements to long-term care. Each state's priorities vary amid the pandemic, but many are advocating for more timely reporting from facilities on their confirmed COVID-19 cases. "It's everyone's top question right now: What's the level of outbreak?" Miller says. "And the lack of transparency and public information about that is concerning."

AARP is pushing for states and the Centers for Medicare & Medicaid Services to require the names of facilities with confirmed cases to be made public daily.

"We believe that data shared on a daily basis, coupled with virtual visitation, will allow both ombudsmen and families to gain a better insight into what really are the circumstances within those facilities," says Elaine Ryan, AARP vice president for state advocacy and strategy integration.

What to do if you have a nursing home complaint or concern

1. Try contacting the facility first, via phone or email. It may be able to directly address your complaint or query quicker than an ombudsman can. Before contacting the facility, learn as much as you can about the situation and be ready to clearly articulate your questions or complaints. Ask about the best way to maintain contact with the facility going forward. Take good notes, including the names of those with whom you've spoken.
2. If unsuccessful, reach out to your ombudsman. "No question is too big or small," Hunter says. "The beauty of the ombudsman program is that we're a jack of all trades." If an ombudsman can't address your query or complaint, you will be directed to someone who can. Also visit the National LTC Ombudsman Program Resource Center, which has up-to-date information on LTC regulations, guidance and ombudsman outreach during the pandemic.
3. Be persistent. Although there will be no delay in the office getting back to you, a lack of access to facilities is making investigations more difficult for ombudsmen. If an issue persists, you can file a complaint with your state survey agency, which inspects nursing homes to determine if they comply with Centers for Medicare & Medicaid Services regulations.

Did you know living with isolation in long-term care can have serious consequences?

Check in regularly with your family and friends residing in Nursing Homes and know who to call if you are concerned for their mental, emotional, and/or physical well-being.

Chemung, Schuyler, and Tompkins County
Long Term Care Ombudsman:

607-274-5498

"WE ARE DEEPLY CONCERNED THAT RESIDENTS ARE CUT OFF FROM LOVED ONES AND VICE VERSA. ... FAMILIES PROVIDE VITAL MONITORING AND OFTEN ESSENTIAL CARE."

— LONG TERM CARE COMMUNITY COALITION



Project CARE



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Aging Better, Together

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

Get Your Farmer's Market Coupons!

Summertime is here, along with a whole slew of fresh fruits and vegetables! The Senior Farmer's Market Nutrition Program assists older adults in purchasing these foods. Any client that is eligible can receive a \$20 coupon booklet that can be used at any of the participating Farmer's Markets.

To be eligible, you must be 60 or over, and receive no more than \$1,968 for a 1-person household and \$2,658 for a 2-person household.

Stop by our office between 9:00am - 12:30pm on Tuesday's, Wednesday's, and Thursday's to pick up your coupon booklet or give us a call at 274-5484.

Stay safe and stay healthy!

Home Energy Assistance Program (HEAP)

The 2019-2020 HEAP Program is continuing

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:

| Household Size | Maximum Gross Monthly Income |
|----------------|------------------------------|
| 1 | \$2,494 |
| 2 | \$3,262 |
| 3 | \$4,030 |

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

Medicare Open Enrollment is Coming!!!

Open Enrollment for Medicare begins on October 15th, and ends on December 7th each year. During this time you can make changes to how you receive Medicare benefits. Be on the look-out for updated information on your current plan, as this is generally mailed out prior to open enrollment. If you're not happy with your current plan or are just curious to see other options for next year, the Tompkins County Office for the Aging has two counselors on staff to assist with navigating Medicare. Give us a call to set up an appointment, 607-274-5482.

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@tompkins-co.org



Dawn Sprague, Project CARE Coordinator and Newsletter Editor

Telephone: 607-274-5499

Email: dsprague@tompkins-co.org

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

