



TOMPKINS COUNTY
OFFICE FOR THE AGING

Aging Better, Together



Fall 2019

Vol. 35

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 

Caregiver Support Group
Last Thursday of each month
5:30 - 7:00
Brookdale
103B Bundy Rd. Ithaca

Facilitated by Robert Levine, LMSW. A support group for caregivers which includes a light meal. To RSVP, or for further information, contact Robert Levine at 256-5094 or by email at rlevine@brookdale.com.

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.

Feeling Stretched?

Let's Face It...

Caring for someone with illnesses such as dementia, heart disease, Parkinson's disease, stroke, or chronic cancer can be stressful physically, emotionally, and financially.



*Balance Your
Life*

Powerful
Tools
for **Caregivers**

Fall 2019

Powerful Tools for Caregivers Class

Powerful Tools for Caregivers is a six-week educational program designed to provide you with tools you need to take care of *yourself*.

You will learn to:

- Reduce stress
- Improve self-confidence
- Better communicate your feelings
- Balance your life
- Increase your ability to make tough decisions
- Locate helpful resources

The program consists of 90-minute class sessions offered weekly for six consecutive weeks.

This class is offered free of charge to those caring for spouses, parents or other adult relatives/friends. (It is not intended for professional caregivers.)

**Thursdays, September 19th—October 24th
2:00 PM—3:30 PM**

**At Tompkins County Office for the Aging
214 W. MLK Jr. / State St.
Ithaca, NY 14850**

Register as early as possible as class size is limited.

**To register or inquire about the program, call the
Tompkins County Office for the Aging:
607-274-5482**

Fall 2019 Caregiver Workshops

Understanding Alzheimer's and Dementia

Monday, September 23rd from Noon-1:00 at The Tompkins County Office for the Aging.

Learn About:

The impact of Alzheimer's.

The difference between Alzheimer's and dementia.

Alzheimer's disease stages and risk factors.

Current research and treatments available to address some symptoms.

Alzheimer's Association resources.

Understanding and Responding to Dementia Related Behavior

Monday, October 21st from 11:00-Noon at The Tompkins County Office for the Aging.

Overview:

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.

Effective Communication Strategies

Monday November 4th from 11:00 – Noon at The Tompkins County Office for the Aging.

Overview:

Communication is more than just talking and listening – it's also about sending and receiving messages through attitude, tone of voice, facial expressions and body language. As people with Alzheimer's disease and other dementias progress in their journey and the ability to use words is lost, families need new ways to connect. Join us to explore how communication takes place when someone has Alzheimer's, learn to decode the verbal and behavioral messages delivered by someone with dementia, and identify strategies to help you connect and communicate at each stage of the disease.

To register for any of these workshops, please contact The Tompkins County Office for the Aging at 274-5491.



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.**



TOMPKINS COUNTY
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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!



Caring for Adults with Cognitive and Memory Impairment

Caregiving: A Universal Occupation

Most people will become caregivers—or need one—at some point in their lives. A caregiver is anyone who provides basic assistance and care for someone who is frail, disabled, or ill and needs help. Caregivers perform a wide variety of tasks to assist someone else in his or her daily life, for example, balancing a checkbook, grocery shopping, assisting with doctor’s appointments, giving medications, or helping someone to eat, take a bath, or dress. Many family members and friends do not consider such assistance and care “caregiving”—they are just doing what comes naturally to them: taking care of someone they love. But that care may be required for months or years, and may take an emotional, physical, and financial toll on caregiving families.

For some people, caregiving occurs gradually over time. For others, it can happen overnight. Caregivers may be full- or part-time; live with their loved one, or provide care from a distance. For the most part, friends, neighbors, and most of all, families, provide—without pay—the vast majority of care.

Many American families care for an adult with a cognitive (brain) impairment. Cognitively-impaired people have difficulty with one or more of the basic functions of their brain, such as perception, memory, concentration, and reasoning skills. Common causes of cognitive impairment include Alzheimer’s disease and related dementias, stroke, Parkinson’s disease, brain injury, brain tumor, or HIV-associated dementia. Although each disorder has its own unique features, family members and caregivers often share common problems, situations, and strategies.

Caregiving and Cognitive Impairments

We know that cognitive and memory impairments can change how a person thinks, acts, and/or feels. These changes often present special challenges for families and caregivers. An ordinary conversation, for example, can be quite frustrating when your loved one has difficulty remembering from one moment to the next what has been said.

Individuals with moderate to severe dementia or another cognitive impairment often require special care, including supervision (sometimes 24 hours a day), specialized communication techniques, and management of difficult behavior. They may need help with activities of daily living (called “ADLs”), such as bathing, eating, transferring from bed to a chair or wheelchair, toileting, and/or other personal care.

Challenging Behaviors

Individuals with cognitive impairment may experience a range of behavioral problems that can be frustrating for caregivers. These might include communication difficulties, perseveration (fixation on/repetition of an idea or activity), aggressive or impulsive

behaviors, paranoia, lack of motivation, memory problems, incontinence, poor judgment, and wandering. Some people may develop behavioral problems early on, while others go their entire illness with only minor issues. Most cognitively-impaired persons fall somewhere in the middle, having good days and bad days (or even good or bad moments). Anticipating that there will be ups and downs, and maintaining patience, compassion, and a sense of humor will help you cope more effectively with difficult behavior. It's important to remember that it's the disease, not the person, causing the behavior.

Helpful suggestions for managing these problems include communication techniques, such as keeping language simple and asking one question at a time. Break down tasks and questions. For example, instead of asking, "would you like to come in and sit down and have a snack?" use simple statements such as, "sit down here," and "here's a snack for you." Allow some time to respond for each question and request.

Wandering and poor judgment may signal the need for 24-hour supervision. Be sure to review the home safety checklist and know whom to contact in your community in case of an emergency. If wandering or aggressive behaviors are problems, you may need to contact emergency, police, fire, or medical systems.

Ten Steps to Get You Started

Whether you have moved into the role of caregiver gradually or suddenly, you may feel alone, unprepared, and overwhelmed by what is expected of you. These feelings, as well as other emotions—fear, sadness, anxiety, guilt, frustration, and even anger—are normal, and may come and go throughout your time of providing care. Although it may not seem possible, along with challenges will come the unanticipated gifts of caregiving—forgiveness, compassion, courage—that can weave hardship into hope and healing.

Each caregiving family faces unique circumstances, but some general strategies can help you navigate the path ahead. As a traveler in new terrain, it is wise to educate yourself as best you can about the landscape and develop a plan accordingly, with the flexibility to accommodate changes along the way. Below are ten steps to help you set your course.

Step 1. Lay the foundation. Establishing a baseline of information lays the groundwork for making current and future care decisions. Talk with your loved one, family, and friends: What was Mom "normally" like? How has she changed? How long has she been forgetting to take her medicine? When did she stop paying her bills? Answers to questions such as these help create a picture of what is going on and for how long. This basic information not only gives you a realistic view of the situation, but also provides an important foundation for professionals who may be called in to make a more formal assessment.

Step 2. Get a medical assessment and diagnosis. It's very important for your loved one to get a comprehensive medical exam from a qualified health care team that reviews both physical and mental health. Many medical conditions can cause dementia-like symptoms, such as depression and medication interactions. Often these conditions can be reversed if they are caught early enough. Additionally, new drug treatments for diseases such as Alzheimer's and Parkinson's diseases may be most effective in the early stages of the disease. A confirmed diagnosis is essential in accurately determining treatment options, identifying risks, and planning for the future. Take your loved one to a memory disorder clinic, if one exists in your community, to get an accurate diagnosis.

Step 3. Educate yourself, your loved one, and your family. Information is empowering. Talk to doctors, health and social service professionals, and people going through similar experiences. Read books and brochures. Do research at the library and on the Internet. Learn how the disease progresses, the level of care that will be needed, and what resources may be available to help. Keep a notebook and a file folder of information you collect that you can refer back to when needed. Knowledge will increase your confidence and may reduce the anxiety and fear that many of us feel in the face of the unknown.

Step 4. Determine your loved one's needs. Care assessment tools include a variety of questionnaires and tests designed to determine the level of assistance someone needs and establishes their personal preferences for care (e.g., bathing in the morning rather than the afternoon). Each situation is different. While one person in the beginning stages of Alzheimer's may need assistance with grocery shopping and bill paying, another in later stages may have problems with dressing, eating, and hygiene.

Assessments usually consider at least the following categories:

- **Personal care:** bathing, eating, dressing, toileting, grooming
- **Household care:** cooking, cleaning, laundry, shopping, finances
- **Health care:** medication management, physician's appointments, physical therapy
- **Emotional care:** companionship, meaningful activities, conversation
- **Supervision:** oversight for safety at home and to prevent wandering

Some hospitals, Area Agencies on Aging (AAAs), city or county agencies, Caregiver Resource Centers, or other government or private organizations offer consultation and assessments specifically designed for older people (called geriatric or needs assessments) for little, if any, cost. Another option is hiring, for a fee, a geriatric care manager or licensed clinical social worker. (See Resources for help in locating someone near you.) These professionals can be helpful in guiding you to the best care

in your area, advise you on community resources, assist in arranging for services, and provide you and your loved one with continuity and familiarity throughout the illness.

Step 5. Outline a care plan. Once your loved one has received a diagnosis and completed a needs assessment, it will be easier for you, possibly with help from a professional, to formulate a care plan—a strategy to provide the best care for your loved one and yourself. It’s a good idea to take some time to think about both short- and long-term needs.

This plan will always be a “work in progress,” as your loved one’s needs will change over time. To start developing a plan, first list the things you are capable of, have time for, and are willing to do. Then list those things that you would like or need help with, now or in the future. Next, list all your “informal supports”—that is, siblings, other family, friends, neighbors—and think about how each person might be able to provide assistance. List any advantages and disadvantages that might be involved in asking these people to help. Write down ideas for overcoming the disadvantages. Repeat the list for “formal” support (e.g., community services, paid home care workers, day programs).

It is important to set a time frame for any action or activities planned. Also, it is wise to have a back-up plan should something happen to you, both for the short-term and the long-term.

Step 6. Look at finances. Most people prefer to keep their financial affairs private. In order to best prepare and provide for a loved one’s care; however, you will need to gain a full understanding of his or her financial assets and liabilities. This transition can be uncomfortable and difficult. Consider having an attorney or financial planner assist you through the process. Assistance from a trained professional may reduce family tension and, if desired, provide you with a professional financial assessment and advice. Try to include your loved one as much as possible in this process.

Next, develop a list of financial assets and liabilities: checking and savings accounts, Social Security income, certificates of deposit, stocks and bonds, real estate deeds, insurance policies and annuities, retirement or pension benefits, credit card debts, home mortgages and loans, and so forth. It’s best to keep all these records in one or two places, such as a safety deposit box and a home file cabinet, and regularly update them. Keep a record of when to expect money coming in and when bills are due. You may need to establish a system to pay bills—perhaps you’ll need to open a new checking account or add your name to an existing one.

Step 7. Review legal documents. Like finances, legal matters can also be a delicate, but necessary, subject to discuss. Clear and legally binding documents ensure that your loved one’s wishes and decisions will be carried out. These documents can authorize you or another person to make legal, financial, and health care decisions on

behalf of someone else. Again, having an attorney bring up the issue and oversee any necessary paperwork can take the pressure off of you, as well as provide assurance that you are legally prepared for what lies ahead.

Other legal documents that you will want to find and place in an accessible location include Social Security numbers, birth, marriage and death certificates, divorce decrees and property settlements, military records, income tax returns, and wills (including the attorney's name and executor), trust agreements, and burial arrangements.

At some point, you may need to determine eligibility for such public programs as Medicaid. It's helpful to speak with an elder law specialist. Information about low-cost elder legal services may be available through the Area Agency on Aging in your community.

Step 8. Safety-proof your home. Caregivers often learn, through trial and error, the best ways to help an impaired relative maintain routines for eating, hygiene, and other activities at home. You may need special training in the use of assistive equipment and managing difficult behavior. It is also important to follow a safety checklist:

Be aware of potential dangers from:

- Fire hazards such as stoves, other appliances, cigarettes, lighters, and matches
- Sharp objects such as knives, razors, and sewing needles
- Poisons, medicines, hazardous household products
- Loose rugs, furniture, and cluttered pathways
- Inadequate lighting
- Water heater temperature—adjust setting to avoid burns from hot water
- Cars—do not allow an impaired person to drive
- Items outside that may cause falls, such as hoses, tools, gates, uneven pavement
- Loose clothing and foot wear that may cause falls

Be sure to provide:

- Emergency exits, locks to secure the house, and, if necessary, door alarms or an identification bracelet and a current photo in case your loved one wanders
- Bathroom grab bars and grips, non-skid rugs, mats, paper cups rather than glass
- Supervision of food consumption to ensure proper nutrition, and to monitor intake of too much or too little food
- Emergency phone numbers and information
- Medication monitoring
- Supervision of alcohol and drug use for fall prevention and proper nutrition

Step 9. Connect with others. Joining a support group will connect you with other caregivers facing similar circumstances. Support group members provide one another with social and emotional support, as well as practical information and advice about local resources. Support groups also provide a safe and confidential place for caregivers to vent frustrations, share ideas, and learn new caregiving strategies. If you can't get away from the house, online support groups offer opportunities to connect with other caregivers nationwide. Another way to meet others going through a similar experience is by attending special workshops or meetings sponsored by organizations such as the local chapter of the Alzheimer's Association or Multiple Sclerosis Society.

Step 10. Take care of yourself. Although this step appears last on this list, it is the most important step. Caregiving is stressful, particularly for those caring for someone with dementia. Caregivers are more likely than their non-caregiving peers to be at risk for depression, heart disease, high blood pressure and other chronic illnesses, even death. Caregivers of persons with dementia are at even higher risk for poor health. The following simple, basic preventative healthcare and self-care measures can improve your health and your ability to continue providing the best care for your loved one.

Practice daily exercise. Incorporating even a small amount of regular exercise into your daily routine can do wonders—it can improve your night's sleep, reduce stress and negative emotions, relax muscular tension, and increase your mental alertness and energy levels. Recent research shows health benefits from walking just 20 minutes a day, three times a week. Talk to your doctor about an exercise routine that is best for you.

Eat nutritious meals and snacks. Caregivers often fall into poor eating habits—eating too much or too little, snacking on junk food, skipping meals and so on. Much of eating is habit, so make it a point each week to add a new healthy eating habit. For example, if breakfast is simply a cup of coffee, try adding just one healthy food—a piece of fresh fruit, a glass of juice, whole-grain toast. Small changes add up, and can be realistically incorporated into a daily schedule.

Get adequate sleep. Many caregivers suffer from chronic lack of sleep, resulting in exhaustion, fatigue, and low energy levels. Depleted physical energy in turn affects our emotional outlook, increasing negative feelings such as irritability, sadness, anger, pessimism, and stress. Ideally, most people need six to eight hours of sleep in a 24-hour period. If you are not getting enough sleep at night, try to take catnaps during the day. If possible, make arrangements to get at least one full night's rest each week or several hours of sleep during the day. If the person you care for is awake at night, make arrangements for substitute care or talk to his or her physician about sleep medication.

Get regular medical check-ups. Even if you have always enjoyed good health, being a caregiver increases your risk for developing a number of health problems. Regular medical (and dental) check-ups are important health maintenance steps. Inform your doctor of your caregiving role and how you are coping. Depression is a common and treatable disease. If you are experiencing symptoms such as a lingering sadness, apathy, and hopelessness tell your doctor.

Take time for yourself. Recreation is not a luxury, it is a necessary time to “re-create”—to renew yourself. At least once a week for a few hours at a time, you need time just for yourself—to read a book, go out to lunch with a friend, or go for a walk.

Article by Family Caregiver Alliance in cooperation with California’s statewide system of Caregiver Resource Centers.



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Aging Better, Together

Project CARE

Project CARE is a **friendly visitor program**. Project CARE provides companionship by having a volunteer make a weekly visit. Volunteers can provide conversation over coffee or tea, play games, go for a walk, work on a puzzle together, help with paperwork, organization, help with gardening, do a cooking or baking project together, manicure, and so much more. Project CARE can be a great comfort to Seniors and can provide in-home support to family caregivers. Volunteers provide opportunities for socialization to those who are homebound and isolated.

Project CARE is currently working on establishing two new options to the program that we hope to be able to offer in the near future;

- On-call option; to meet a one time or short-term need such as grocery shopping due to illness or injury, light yard work, running an errand, one-time respite and more for those who do not want to commit to a weekly visit.
- Telephone Reassurance Program; weekly check-in phone calls to Seniors, especially those Seniors that are socially isolated.

If you are interested in this program please contact:

Dawn Sprague at (607) 274-5499 to be added to the list and so we may collect your information.

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:

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 Coming Soon!

Medicare Open Enrollment begins October 15th until December 7th. During open enrollment, you can change how you receive Medicare. You can switch to a Medicare Advantage plan or back to traditional Medicare, you can change your drug plan, or simply compare plans for 2020 to make sure you're comfortable with the coverage you have. Call the Tompkins County Office for the Aging at 274-5482, or Lifelong at 273-1511, to schedule an appointment with a Medicare Counselor to review your options.

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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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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