



In Support of Caregivers

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

Summer 2015

Vol. 27, Number 2

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The Caregivers' Resource Center

Striving to support those who are caring for family and friends

- Telephone support available Monday through Friday, 8:30 AM to 4:30 PM
- Referrals to respite services and other community-based services for caregivers and their care-receivers
- Volunteer Support for Caregivers through Project CARE
- This quarterly newsletter: *In Support of Caregivers**
- Powerful Tools for Caregivers* classes
- Directory: “Resources for Caregivers in Tompkins County”*
- Caregiver Support groups
- Periodic workshops for family caregivers
- Alzheimer's education and support
- Monthly “Dementia Caregivers' Bulletin” (sent electronically)
- Lending library of books on caregiving topics
- Speakers available to talk to community and employee groups on caregiving topics



*These publications are also available on-line at: www.tompkinscountyny.gov/cofa

(Click on “Local Resources for Older Adults” or “Newsletters”)

Local Caregiver Support Services

full day (\$45) or half-day (\$31 with lunch, \$22 without lunch).

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging

David Stoyell (274-5492)

Katrina Schickel (274-5491)

The Caregivers' Resource Center & Alzheimer's Support Unit

offers family caregivers information, consultation services, support groups, workshops, this newsletter, and a lending library of books on family caregiving topics. Stop by or call for an appointment.



Volunteers from **Project CARE** offer caregivers a needed break and help out 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 Katrina to discuss your needs.

Caregiver Counseling

Family and Children's Service

Ann Dolan (273-7494)



A caregiver counselor will meet with family caregivers periodically in her office or at their home and help them work through complex caregiving issues or provide emotional support. No charge. Donations accepted.

Adult Day Program

Longview Adult Day Community

Monday thru Friday, 9 AM- 3 PM

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:

Support Groups



Caregiver Support Group

3rd Tuesday of each month

6:30 PM-8:00 PM

Family and Children's Service

127 W. Martin Luther King Jr./State St., Ithaca.

Facilitated by Ann Dolan, LCSW. Especially for caregivers of older adults. Call for information, 273-7494. Important: Please ring buzzer located next to the front door for entry.

Alzheimer's Support Group

4th Tuesday of each month

1:00-2:30 PM

Tompkins County Office for the Aging

214 W. Martin Luther King Jr./State St., Ithaca

Facilitated by David Stoyell. Open to anyone caring for a relative or friend with significant memory impairment. Call 274-5492 for more information.

Other Alzheimer's Caregiver Groups

3rd Wednesday of each month at 5:30 PM

at Lifelong, 119 W. Court St.. Ithaca. For info., call the Alzheimer's Association at 330-1647.

Last Thursday of the month, 5:30 PM Dinner, 6:00-7:00 speaker at Clare Bridge, 101 Bundy Rd., Ithaca. RSVP each month you plan to attend- 351-7857.

3rd Wednesday of the Month, 12:30-1:30 PM

at Walden Place, Cortlandville. Call 756-8101.

Companion care for your loved one available during the meeting.

Helping an Older Adult with their Health Insurance

Sometimes family caregivers need to help a loved one with their health insurance—helping them stay on top of bills, researching plans to make coverage changes when advisable, understanding which health providers are “in network” and “out of network” for their insurance plan, and so on.

Talking with Insurers...

If you want to call a loved one’s insurance company about their coverage, your loved one will need to be nearby to give permission for the company representative to speak to you. It may be a good idea to ask the company to send their “Consent for Release of Protected Health Information Form,” which your loved one can sign and return giving the company permission to speak to you at any time.

...and Sales Reps

For the past 10 years, Medicare beneficiaries have had the option of getting their health coverage through private insurance companies selling “Medicare Advantage” health plans. While most sales representatives perform a valuable service in explaining and helping people sign up for coverage, there are a few bad actors who do not act in the client’s best interest. The most common complaint that I have received from Medicare beneficiaries is that the sales representative signed them up for a plan without knowing whether their doctors and hospital were “in network” or “out of network.” Outpatient surgery or observation stays at an “out-of-network” hospital can cost hundreds or thousands of dollars more in co-pays than the same care received at an “in-network” hospital.

Bills and Notices

Early in October each year, those who belong to Medicare Advantage health plans or Medicare Prescription drug plans get a notice of changes in coverage for their plans that will start the following January. It is important to review these notices to see what changes in premium, deductibles and co-pays there will be. If their health has changed, perhaps their coverage needs have changed also. Between October 15 and

December 7 is the “Annual Open Enrollment Period” when Medicare beneficiaries are allowed to compare and change plans.

Can’t Afford Prescriptions?

People with income below \$1,345/month (\$1,813 for a couple) qualify for the “Medicare Savings Program” which will pay their Medicare B premium (currently \$104.90/month) and their Medicare drug premium (up to \$36.94/month). They also qualify for full extra help with drug co-pays at the pharmacy (maximum of \$2.65 for generics and \$6.60 for brand names).



Help for Middle Income Folks?

What about middle income folks who have unaffordable drug costs? The New York State EPIC Program has expanded eligibility so that individuals who earn up to \$75,000/year (\$100,000/year for couples) can benefit from the program if they take drugs with large co-pays. The EPIC program is open to people, 65 and older, who have Medicare Drug coverage. For people who have income under \$23,000 for the prior year (\$29,000 for couples), the EPIC Program will pay most or all of the premium for a Medicare drug plan or Medicare Advantage plan that covers drugs. It also pays most of the co-pays after the EPIC member has met the out-of-pocket deductible if required. The deductible is higher for those with higher incomes, but the EPIC program has been a big help even to middle income people who have huge co-pays for very expensive medications that they need.

Health Insurance Counseling

The complexities of Medicare and other health insurance can be daunting to anyone, not only to older adults who may need assistance in managing their affairs. Fortunately, free health insurance counseling for Medicare beneficiaries or their caregivers is available. In Tompkins County, call to make an appointment to speak to a HIICAP (Health Insurance) Counselor at Lifelong (273-1511) or the Tompkins County Office for the Aging (274-5482).

Feeling Stretched?

Let's Face It...

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



Balance Your Life

Powerful
Tools
for **Caregivers**

Fall 2015

Powerful Tools for Caregivers Classes

Powerful Tools for Caregivers is a six-week educational program designed to provide you with the 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 six - 90 minutes class sessions held weekly and is offered free of charge to caregivers.

Not intended for professional caregivers

September 30 — November 4

(6 Wednesdays) 10:30 AM— Noon

at the Office for the Aging

214 W. Martin Luther King Jr./State Street

Pre-registration is required and attendance at the first class is mandatory.

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

Powerful Tools for Caregivers is offered by the Caregivers Resource Center of the Tompkins County Office for the Aging, with support from Cornell University, and NY Connects /Long Term Care Services Unit of the Tompkins County Department of Social Services

Changing Places: Should Your Parents Move in with You?

Lisa's mother, Ruth, has been living alone since her father died five years ago. Ruth has been active at church and eats lunch at the local senior center a couple times a week. Lisa does the food shopping, takes Ruth to doctors' appointments and has her over to her house for dinner, usually once a week.

Lisa has begun to notice, however, that when she is at her mother's house, it is not as clean as it used to be. Several times lately she's noticed a pile of dishes and a burned saucepan in the sink—something her mother would never have done before. The other day she saw a bright green envelope on the dining room table, which was a notice that the utility bill had not been paid.



Slowly, Lisa has begun to think that her mother may have problems with her memory, and may not be able to live safely at home alone any more. Having always been close to her mother, she had assumed that her mother would eventually come live with her. But now Lisa has to think about what that would mean.

Making the decision to move a parent into your home is not necessarily as clear-cut as it would seem. A number of situations and questions arise that need addressing.

Relationships

- How will I talk to my mother about moving?
- How do my spouse and children feel about moving mother into our home and how will it change our lives together?
- What things will be easy for us to negotiate in living together and what things will be hard?
- What are the limits of my ability to care for mother at home and what if I have to put her in a nursing home?
- How will my siblings feel and how much help will they give me in caring for mother?

- Will her friends come to visit her at my house or will she be dependent on me for all her socializing?
- What are my needs for privacy and alone time?

Adapting Your Home

- Where will mother sleep— in my daughter's room, convert the den, build an addition?
- What assistive devices do I need— grab bars in the bathroom, raised toilet seat, ramps, etc.?
- Does mother smoke or drink and will that be a problem for me?
- Does mother have a pet that will be coming with her and how will I cope with caring for it?

Money

- What will the financial arrangement be? Should I charge rent and have expenses for her to cover?
- How will my siblings feel about the financial arrangement?
- Will my work situation have to change, and if so, how will I cover the bills?

Time

- Will mother need care during the day, and if so, how will it be provided?
- How will I juggle my job, childcare, marriage and taking care of mother?
- When in my day will I be able to make the phone calls needed to make arrangements for mother?
- When will I have time for myself?

Personal Care

- How comfortable am I with helping mother bathe or changing an adult's diaper?
- Do I know what to expect over time as mother's condition changes?
- How is my health and will I be able to take care of myself as well as my mother?
- Am I willing to accept respite care to get a break?

(Reprinted with permission from the website of the Family Caregiver Alliance: www.caregiver.org)

A Guide to Taking Care of Yourself

The care you give to yourself is the care you give to your loved one, said a caregiver. Absolutely the easiest thing for someone to say and the hardest thing to accept is the advice to take care of yourself as a caregiver. It is often hard to see beyond the care tasks that await you each morning.

What is shown by study after study is that caregiving compromises health. About 60% of caregivers show signs of clinical depression, and caregivers take more prescription medications, including those for anxiety and depression, than others in their age group. Reluctance in asking for and accepting help is a major barrier to getting necessary respite and support. Who has time to think about breaks when there is a diaper that needs to be changed? Seventy-five percent of caregivers in America are women, some taking care of spouses/partners, some are adult children taking care of parents, and some parents taking care of adult children. What does taking care of yourself mean, why is it so hard to do, and how do you do it?

*Taking care
of yourself
isn't selfish.*

- **Support.** Support and coping comes in many forms- prayer, talking to family, friends or professionals, saying "yes" to offers of help, taking walks, reading a book, eating hot fudge sundaes. But most caregivers end up withdrawing from friends and family and feeling isolated and as if no one understands. Support groups can be an important source of understanding and connection.
- **Guilt.** Guilt that "I should" do this or be able to do it, guilt that your loved one won't get as good care if you aren't doing it, guilt that something will happen if you are away, guilt about having a good time when someone else is not. As there is no "perfect parent," there is

no such thing as a "perfect" caregiver. And you are not selfish to sometimes think about yourself and your needs and feelings. Although caregivers feel guilty when they get angry or frustrated, these feelings are ok and a way to know how well you are coping. "How can I say it is difficult when I really love this person?" questioned the husband of a client.

- **Setting limits.** Learn to ask for help. The often-heard question, "Is there anything you need?" has but one answer: Yes. "Yes, I need a meal, I need someone to stay here so I can go out, I need some time by myself, I need flowers, I need help in the garden, I need some groceries." Learn to say "no" to requests that are draining rather than nurturing, such as hosting holiday meals. You can still make choices about your life and what is right for you and you do still have some control.
- **Your Body.** Not getting enough sleep is a major cause of illness and stress in caregivers. Exhaustion is one of the main complaints, leading to irritability and then inappropriate anger which then leads to more guilt. Talk with your physician about medication for either yourself or your loved one to help with sleeping through the night. Know the limits of your own endurance and strength. Make sure you have regular check ups and that those "little concerns" about your health are looked into. Exercise is even more important as it gives you a break, combats depression and helps you maintain health.



When I talk with caregivers, one of their fears is worrying about what will happen to their loved one if something happens to them. Worrying doesn't help. Taking better care of your health does.

- **Education.** Learn as much as you can about the illness so that you can understand what is

happening. Attend a workshop or support group, not just for emotional support but also to learn caregiving tricks to make caregiving easier. You can't know it all; this is a job you weren't trained to do. Contact someone who can help you connect with community resources and use them.

- **Emotional Health and Respite.** Taking care of yourself may mean dealing with family problems. How can you make your siblings pull their weight? Possibly you can't, and learning how to have a family meeting or work around them is essential for survival. One family actually has a chart and marks off what each does so no one can say, "You aren't doing your share." It is easy to become overwhelmed, thus the need for breaks. One caregiver told me that she deals so much better with her husband when he has been at day care, because when he comes home, she is not already frustrated by him. Without breaks, you begin to question yourself, feel inadequate and experience burn out. Caregivers are often mourning the loss of the person "who used to be." Grief and loss need to be acknowledged.

One of the stressors of caregiving is seeing no end to the situation. Having a life and connections outside of caregiving helps you to maintain perspective, so that caregiving doesn't become one's only reality. You might be interested in the Family Caregiver Alliance's *Taking Care of YOU: Self Care for Family Caregivers*, a guide to assist caregivers in facing day-to-day challenges. (You can view it online at <https://caregiver.org/Taking-care-you-self-care-family-caregivers>.)

Meanwhile, your best defense is a sense of humor. Find people or situations to laugh at daily. It refreshes the soul and renews your spirit.

Reprinted with permission from the website of the Family Caregiver Alliance found at <https://caregiver.org>

New in the Lending Library



A large selection of books on various family caregiving topics can be borrowed from the lending library at the Office for the Aging. Newly acquired books include:

Can't We Talk about Something More Pleasant? A memoir by Roz Chast. Bloomsbury, 2014

Roz Chast admits that she and her parents were practitioners of denial: if you don't think about death, it will never happen. In this account, longtime *New Yorker* cartoonist Chast combines drawings with family photos and documents, chronically the "long good-bye."

The Kinship Parenting Toolbox, edited by Kim Phagaan-Hansel, EMK Press, 2015.

Through the book you will find wisdom from people who are caring for grandchildren or other children in kinship relationships. Topics ranging from legal and financial to relationships, emotions, discipline, schools, and the teen years.

Second Wind, Dr. Bill Thomas, Simon & Shuster, 2014.

"A beautifully crafted narrative on the forces that have shaped the Baby Boom generation and a road map for how this massive group can now use their accumulated wisdom and elderhood as a potent force for cultural renewal, connection and deep healing."

Aphasia Support Group

An *Aphasia Support Group* is meeting on a weekly basis every Friday From 9:00– 10:30 AM throughout the summer.

It meets in the conference room of the Tompkins County Office for the Aging, 214 W. Martin Luther King Jr./State St., Ithaca.

difficulty understanding
difficulty reading
difficulty speaking
difficulty writing
APHASIA
Language Disability Caused by Brain Injury

Depression in Later Life

Depression is not a normal part of aging. It is a treatable medical illness. Aging involves a progressive series of losses. A person may lose their role as a worker, parent or spouse. Their support system may decrease when an individual outlives close friends and relatives. When formerly-held roles are lost a person can have a loss of self-worth and no sense of what to do with their lives.

When someone is already ill, depression can be more difficult to recognize and more difficult to endure. Certain chronic illnesses, which are more prevalent in the elderly, are linked to depression, including Parkinson's, strokes, and Alzheimer's.

Depression is not a short-lived mood. A person suffering from depression may withdraw or avoid activities. They may say they don't feel well or that it is too difficult to do activities they enjoyed in the past. Other symptoms of late-life depression include:

- Persistent sadness (lasting two weeks or more)
- Feeling slowed down
- Excessive worries about finances and health problems
- Frequent tearfulness
- Feeling worthless or helpless
- Weight changes
- Pacing and fidgeting
- Difficulty sleeping
- Difficulty concentrating
- Physical symptoms (pain or gastrointestinal problems)

Depression affects fifteen of every one hundred adults over 65. The good news is that even with

severe illness or when a person is in terminal stages of a disease, depression can be treated. Mild or moderate depression can be treated with counseling or psychotherapy. Supportive counseling can include religious or peer counseling. It is important for the person to find an individual with whom they feel comfortable and who has experience with older patients.

Antidepressant medication can help people feel better by controlling some symptoms. Antidepressants work by increasing the level of neurotransmitters in the brain. Feelings of pain and pleasure are a result of neurotransmitter function. When there is an imbalance, depression may result. In cases of severe depression, electroconvulsive therapy (ECT) may be used. It may be considered if a person is not responding to medication or is suicidal.

If you think your loved one may be suffering from depression, contact their health care professional for a complete medical evaluation and referral to a counselor or therapist with geriatric training. Depression is treatable, and when treatment is provided, quality of life for your loved one can be enhanced.



If your loved one cannot travel to a counselor, some home-based services are available from the Geriatric Mental Health Services program of Family and Children's Service of Ithaca, 607-273-7494.

Alzheimer's Notes

Living with Alzheimer's for Caregivers: Early Stage

In the early stage of Alzheimer's disease, families face new questions as they adjust. This workshop is designed to provide care partners with the knowledge, tools and strategies needed to cope with a diagnosis of Alzheimer's or related dementia. Reservations required. Call the Tompkins County Office for the Aging, 274-5492 or email dstoyell@tompkins-co.org.

Pre-registration is required at least 5 days before the program date. Unfortunately, programs with minimal registrations will have to be cancelled. If you do not register, you are still welcome to attend, but please call ahead to confirm the program is still scheduled.

When Monday July 20 11 AM – 3 PM

Where Tompkins County Office of the Aging, 214 W. Martin Luther King Jr./State St., Ithaca

Living with Alzheimer's for Caregivers: Late Stage

The late stage of Alzheimer's may involve significant changes in how the person with the disease is cared for. Learn what to consider, what to do, and what resources are available to ease the transitions that come with the late stages of the disease. Call the Tompkins County Office for the Aging, 274-5492 or email dstoyell@tompkins-co.org.

Pre-registration is required at least 5 days before the program date. Unfortunately, programs with minimal registrations will have to be cancelled. If you do not register, you are still welcome to attend, but please call 800-272-3900 to confirm the program is still scheduled.

When Tuesday September 29, Noon – 3 PM

Where Tompkins County Office of the Aging, 214 W. Martin Luther King Jr./State St., Ithaca

Memory Maker Project

The "Memory Maker Project" plans activities to enrich the lives of those with Alzheimer's and other forms of dementia. For more information on the June 5th events at the Art Mission Theatre in Binghamton, call Christina at 607-240-6204 or email christina@memorymakerproject.org.



The flyer features a decorative top border with colorful triangular bunting. In the center, there is a graphic of a human brain. The text is arranged in a clear, readable layout with various colors and fonts. A pink ribbon graphic highlights the date. The event details are listed in a structured manner, including times, locations, and prices. Logos for partner organizations are displayed at the bottom.

Meet **THE MEMORY MAKER PROJECT**
a project of the Center for Transformative Action.

Friday, June 5th

Learn about & support cultural programs for people living with Alzheimer's and other forms of memory loss in the Southern Tier.

5:15–6:30 pm Discussion & Documentary Viewing
@ The Art Mission Theater
"I Remember Better When I Paint:
Treating Alzheimer's through the Creative Arts"
\$10.00

6–9 pm Gallery Opening @ The Art Mission
FREE

9–midnight After Party @ The Shop
DJ Freeze, DJ Priest & live African drumming
Complimentary appetizers & raffle
\$10.00

Logos: THE SHOP, THE MEMORY MAKER PROJECT, art Mission and Theater, MemoryMakerProject.org

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.
(Open weekdays, 8:30 AM - 4:30 PM)

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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.*

**Click on "Newsletters" to view electronic editions of this newsletter for the past year.*

Family Caregiver Alliance: www.caregiver.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.