



In Support of Caregivers

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

Spring 2018

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The RAISE Family Caregivers Act

In January of this year, with bipartisan support, Congress passed and President Trump signed the *Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act*. This legislation requires the U.S. Secretary of Health and Human Services (HHS) to develop and maintain an integrated national strategy to support family caregivers. Its goal is to identify actions that government, communities, health providers and others can take to support family caregivers:

- Promoting greater adoption of person-centered and family-centered care in health and long-term care settings
- Training for family caregivers
- Respite options for family caregivers
- Ways to increase financial security for family caregivers
- Workplace policies to help family caregivers keep working
- Collecting and sharing of information about innovative family caregiving models
- Addressing disparities and meeting the needs of the diverse caregiving population



Under the RAISE Act, HHS will bring together federal agencies and representatives from the private and public sectors (like family caregivers, health care providers, employers and state and local officials) in public advisory council meetings designed to make recommendations. The agency will have 18 months to develop its initial strategy and then must provide annual updates. Here in Tompkins County, there has been some progress in providing training and respite options for family caregivers. And New York's new “Family Paid Medical Leave Act” now provides more financial support for employed family caregivers. Give us a call here at the Tompkins County Office for the Aging if you have questions about local supports for family caregivers. In the meantime, we hope that a national strategy to support family caregivers produces workable recommendations and that recommendations are implemented to provide family caregiver support that is sorely needed.

Local Caregiver Support Services

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging

David Stoyell (274-5492)

Caryn Bullis (274-5450)

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 Caryn 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 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 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: \$55/day includes lunch and snack.



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, before attending first time. 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

1st Wednesday of each month at 5:30 PM

at Lifelong, 119 W. Court St., Ithaca. For information, call Alzheimer's Assoc: 330-1647

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.

Cancer Caregiver Group

2nd Tuesday of the month, 5:30-7:00 PM

At the Cancer Resource Center of the Finger Lakes, 612 W. State St., Ithaca. For family, friends and caregivers of individuals with Cancer. For info, call 277-0960.

Parkinson's Caregivers Group

1st Monday of the monthly, 11:00 AM- 12:30

PM at the Office for the Aging. Call the Office for the Aging for further information, 274-5492.

Senior Living Expo

Saturday, April 7, 1:00 PM -3:30 PM

at the Ramada Inn, 2310 N. Triphammer Rd., Ithaca

You can choose to attend any of the following presentations. There will also be displays set up by more than 30 organizations with staff from the organization present to answer your questions about the services they offer to older adults and their family caregivers. Free. Pre-registration is not necessary.

At 1:30 PM, choose from the following two workshops:

Community Supports for Aging in Place

Presenter: Lisa Holmes, Director, Tompkins County Office for the Aging

Senior Housing Options in Tompkins County

Presenter: David Stoyell, Aging Services Specialist, Tompkins County Office for the Aging

At 2:30 PM, choose from the following two workshops:

Downsizing

Presenter: Allyson Mooney, Professional Organizer, Lifestyle Organization

Cost-saving Programs for Medicare Beneficiaries

Presenters: Sarah Jane Blake, Outreach Coordinator, NY Statewide Senior Action Council
Nicole Zulu, HIICAP Coordinator, Lifelong



Transition to Assisted Living or Nursing Home: Is it Time?

Wednesday, May 9, Noon– 1:00 PM

at the Office for the Aging, 214 W. Martin Luther King Jr./State St.

Presenter: Suzanne Motheral, Regional Ombudsman Program Coordinator

Suzanne Motheral will discuss the caregivers face in deciding whether a loved one is no longer able to be cared for safely at home. She will also discuss the supportive role the family caregiver can continue to play after a transition of their loved one to assisted living or a nursing home. Ms. Motheral is the Regional Ombudsman Program Coordinator for Chemung, Schuyler and Tompkins Counties. Preregistration is required. Call 274-5492 or email dstoyell@tompkins-co.org.



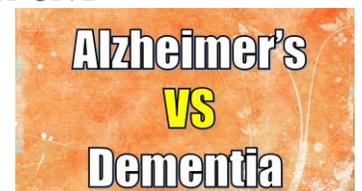
The Basics: Memory Loss, Dementia and Alzheimer's Disease

Wednesday, June 20, Noon--1 PM

at the Office for the Aging, 214 W. Martin Luther King Jr./State St.

Presenter: Staff from the Alzheimer's Association of CNY

This class will cover risk factors, types of dementia, diagnosis, stages of Alzheimer's, treatments and community resources that can help. Free. Bring a brown bag lunch if you wish. Register by calling 274-5482 or email dstoyell@tompkins-co.org or cbullis@tompkins-co.org.



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**

Spring 2018

Powerful Tools for Caregivers Classes

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.

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

Wednesdays, March 21—April 25

10:30 AM — Noon

**at Kendal at Ithaca
Conference Room A**

2230 N. Triphammer Rd., Ithaca

Mondays, March 26 — April 30

6:00 PM—7:30 PM

at McGraw House

221 S. Geneva St., Ithaca

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

Reduce Risk of Phone Scams

In its March 2018 issue, Consumer Reports writes that one of the best ways to reduce robocalls is to use blocking technology which intercepts robocalls before they reach you. Some phone companies offer the service for free or for an added fee. Apps such as Nomorobo are free or cost a dollar or two a month for use on cell phones or VoIP phone service such as Comcast/Time Warner (www.nomorobo.com).



New Medicare Cards

You may have heard by now that Medicare beneficiaries will be getting a new Medicare card that removes Social Security numbers. The cards will be mailed gradually between April 2018 and April 2019, so don't be concerned if some friends or neighbors receive their cards before you or your loved one.



The card will come automatically. **You don't need to do anything to receive it.** If someone calls you or your loved one about it, it is a scammer who will be trying to access your personal information!

Free Legal Help

LawNY (formerly Neighborhood Legal Services) is now able to offer assistance to older adults with making a will and with elder care directives (power of attorney and advance medical directives). People under age 60 are also eligible if they meet income eligibility criteria. In Tompkins County, call 273-3667 or 1-800-724-4170.



United Medical House Calls

A new primary care provider, United Medical House Calls is now providing Tompkins County residents medical care in their homes (or in their apartments at assisted living facilities). It provides an option for those for whom it is a hardship to go to a doctor's office for wellness visits, sick visits, immunizations, etc. They are a Medicare provider and follow their fee guidelines for all visits, testing and treatments. They also provide mobile imaging/tests (EKG, x-rays, ultrasound, urinalysis). To learn more, visit their website at www.medicalhousecalls.com or call (315) 715-1698.



Dental Network Access Program

Five dental practices in Tompkins County and some in neighboring counties participate in the **DENTEMAX** "Dentemax" Dental Network Access Program. Enrollment in the program is \$36.50 per year for single coverage or \$52.00 per year for family coverage (no age limit). Savings may be 35-40% less than the average area fees for dental procedures. This is not dental insurance, but participating dentists typically charge reduced rates to those enrolled in the program. Visit www.heginc.com/dental to find the names of network dentists and network fees for the most common dental services (or to enroll).



Note: Some dentists who don't participate in this program may offer a discounted rate to regular clients who are having trouble affording necessary, but expensive, dental work. It doesn't hurt to ask.

Caregivers Face Difficult Challenges

(The following is excerpted from an article by Dr. Pat Hayes and Jackie Swift. Dr. Hayes is a retired physician and Swift is a freelance writer and editor and former communications manager for Hospicare.)

Caring for someone who is seriously ill is one of the hardest jobs most of us will ever have. Caregivers are showing the depth of their love by supporting their ill loved one, and they want to do the best they possibly can. At the same time, they are faced with a task that can be exhausting, frightening, and isolating. As a physician, I would often see caregivers struggling to do it all for their loved one. I know how strong that impulse can be, but I would always tell them they have to pace themselves. They may be providing care for weeks, months, or even years as their loved one slowly declines.

In an article titled “Caregiving at Life’s End: Facing the Challenges,” the American Hospice Foundation (AHF) offers some suggestions to help caregivers get through the difficulties of their loved one’s last weeks and months. The article emphasizes that caregivers need to realize their ability to help their loved one depends on their own well-being. If you want to be a good caregiver, you can’t get over-exhausted. If you do, you’re more likely to become bitter, abrupt, and angry...As the AHF puts it, “Self-care is part of your job every day.”

Caregivers need breaks once in a while in order to recharge and lower their stress level. It’s common to feel that your loved one needs you 24/7, and so there is no time to do the little things you used to do with friends and family. However, the best thing you can do is not to cut off your contacts. If you’ve been going out



for coffee with your best friend on Thursday mornings for the last 15 years, you should keep that routine. It’s possible to have others come in stay with your loved one for short periods. Sometimes other family or friends will do it. Or, when your loved one is on hospice services, a trained volunteer can ease your burden by sitting with your loved one when you go out.

Another big part of the caregiving experience is the feeling of fear. Your loved one



depends on you for quality of life. What you do can make the difference between pain and comfort, and it feels as if every decision is extremely important...a heavy burden that I’ve seen fill caregivers with fear and distress....As a caregiver, you may fear what may happen at the time of your loved one’s death and your own ability to handle that. This is understandable; we fear what we don’t know.

These types of fears can be calmed by talking with trained professionals, such as your primary doctor or hospice team members, who can give you the information you need to understand what’s happening as your loved one’s health changes...Hospicare and Palliative Care Services, the hospice provider in Tompkins and Cortland Counties, has a mix of team members that are assigned to every person and their family. Along with a primary nurse, who is the main contact and can answer medical questions, the Hospicare team also includes professionals— such as counselors trained in spiritual care and grief—who can help with emotional and spiritual issues like fear.

(You can read the full AHF article on “Caregiving at Life’s End” by visiting the American Hospice Foundation’s website at americanhospice.org/caregiving.)

News and Notes

Improved Vaccine for Shingles

In January of 2018, the U.S. Centers for Disease Control (CDC) formally recommended that all healthy adults, 50 and older, get two doses of a newly approved vaccine for shingles called Shingrix. It is more effective than the older vaccine, Zostavax. Consumer Reports says that health insurers will likely cover the cost of the new vaccine. Even if someone has already received the Zostavax vaccine, the CDC recommends also getting the Shingrix vaccine. For more details, visit



www.consumerreports.org/shingles-vaccine/new-shingles-vaccine-shingrix-what-you-should-know/

In addition to Shingrix, older adults should be talking to their physicians about annual flu vaccinations, pneumonia vaccine, and boosters needed for tetanus and pertussis.

New Family Medical Leave Act

As of January 1, 2018, most employees who work for private employers in New York State are eligible to take Paid Family Leave. Family Leave provides job-protected, paid time off so you can care for a close relative with a serious health condition. You can continue your health insurance while on leave and are guaranteed the same or a comparable job after your leave ends. If you contribute to the cost of your health insurance, you must continue to pay your portion of the premium cost while on Paid Family Leave. For more details, visit www.ny.gov/new-york-state-paid-family-leave/paid-family-leave-information-employees.



CapTel Phones

CapTel phones provide captions for everything the caller says, which is helpful for people who have hearing loss. They also have additional features including adjustable ringer volume, visual cues, speed dial, and more. CapTel phones and phone service are free for those who have hearing loss in New York State. If you would like to have a demonstration of a CapTel phone visit the Finger Lakes Independence Center (FLIC) in Ithaca. They will also assist you to obtain a phone for home use.



FLIC has hundreds of different other types of assistive equipment that people can try out or borrow for a while before they decide whether or not they want to acquire it for ongoing use. Call FLIC at 272-2433 with your questions.

Ted Talk

In an inspirational 9-minute *Ted Talk*, Scott Williams, once a cared-for patient and now a caregiver himself, highlights the invaluable role of informal caregivers -- those friends and relatives who, out of love, go the extra mile for patients in need. The talk is titled: "The Hidden Role Informal Caregivers Play in Health Care,"



www.ted.com/talks/scott_williams_the_hidden_role_informal_caregivers_play_in_health_care.

Note: If you do not have computer access and want printed information sent to you about online resources referenced in this newsletter, give us a call at the Tompkins County Office for the Aging, 274-5492.

Stress and Coping Skills

Dr. Ralph Hesse, a Cortland area psychologist, listed the following situations that family caregivers identified as being particularly stressful at a recent support group meeting that he facilitated:



1. You can be suddenly faced with many important decisions to make; not only involving the care of your loved one, but also everyday decisions that now you have to make. Perhaps your significant other made the decisions involving car repair or medical bills. Now you have to make all the decisions.
2. Enormous responsibilities are placed on you.
3. A tremendous amount of uncertainty about the future occurs, be it long-term or just how the next day is going to turn out.
4. You now have less control of your life than you used to have.
5. There can be a lack of cooperation not only from your loved one, but from other family members or the medical establishment.
6. You lose sleep either from having to be watchful over your loved one, or just through worrying.

Dr. Hesse also lists some of the ideas for reducing stress that caregivers shared at that same meeting:

1. Connect with others. Talk about the issues that bother you. Have some trusted people to talk to who won't judge you.
2. Exercise in some way. Physical activity, even light physical activity, reduces stress.
3. Try to be as flexible as possible. It's hard to be a control freak (if) you have a loved one

with Alzheimer's because you are not going to be able to control things.

4. This is a hard thing to do, but sometimes you have to surrender. I don't mean surrender in terms of helping your loved one, I mean surrender things you think you might have wanted to do on a particular day. If you can't go out to dinner with friends because responsibilities to your loved one keep you at home, you may be less stressed (and angry) if you just surrender that fun evening.
5. Sometimes it is OK, if you find yourself overstressed, to take medication for it. There is absolutely no shame in asking your doctor for an anti-anxiety medication if you find yourself overstressed. Don't view taking such a medication as a sign of weakness. It isn't!
6. Try to become as organized as possible. When things are organized, issues sometimes become less stressful.
7. Try to spend some time each day on a hobby of yours. Don't abandon your passions.

Of course, support groups are one way to connect with others. You don't have to agree with all the ideas expressed by others at support group meetings. Just the act of sharing your stressful situation with others who can empathize with you is a great help. Any ideas that surface that you can implement are a bonus.



Area support group opportunities for family caregivers are listed on page two. Call the Caregivers' Resource Center at the Tompkins County Office for the Aging to discuss options that may be helpful to you.

Alzheimer's Page

Tips for a Better Visit

Dementia experts remind us that what we do when visiting is less important than that we are doing it together. Nevertheless, when thinking about activities to do consider the Three P's: **Pleasure**—that you both enjoy the time; **Participation**—that you both get involved as much as possible; and **Presence**—that you show you want to be with the person.

In an article that appeared on Caring.com, dementia care specialist Vivian Komer suggests engaging people in the moment, whatever that might be. "Be perceptive about what their living environment is like...instead of asking them too many questions about their recent activities, comment on objects in the room or in nature around you." "Isn't that a beautiful picture?" "Aren't those beautiful colors?" "Look at the lovely cloud formations." She suggests that using concrete objects can be a conduit to a conversation. We can all benefit from pausing our fast-paced work and agendas to slow down, live in the moment, and be perceptive about the beauty in our environment.

Communication Tips

When visiting, try to talk directly to the person, not about them to a caregiver or family member. Make eye contact and use body language, which becomes more important when language diminishes. Speak in short sentences, expressing one idea at a time. Use humor. The person with dementia may forget your name but they will remember they like you. If the person gets fixated on something that is agitating them, consider trying to shift the conversation to something else rather than trying to convince them not to be bothered by it.

Just as you try not to judge the person with dementia for any repetition, failure to remember, or less than proper table manners, it is important not to judge yourself too harshly either. Ms.

Komer writes: "It's not like any of us are prepared for the challenge...of trying to connect with a loved one with dementia.... it's not like you go to school for this." We just need to "get up to speed as fast as we can" when faced with the situation.

Below you will find some activities for someone in the early stages, and



others are appropriate for those in later stages. After modifying it to include your own ideas, it might be helpful to keep such a list available so family members and friends may use it.

1. Bring pictures of family and friends from days gone by.
2. Make a photo album from family pictures.
3. Bring vacation photos, souvenirs, and tales of your travels.
4. Look at magazines that have a lot of large, colorful pictures.
5. Read religious or inspirational articles, magazines, or books.
6. Bring things related to the season or upcoming holiday to do or talk about.
7. Sing, hum, or whistle a favorite song together.
8. Listen to music.
9. Do simple jigsaw puzzles.
10. Bring artwork from the children in the family.
11. Do arts and crafts together such as painting or knitting, keeping tools and patterns simple.
12. Bring a pet to visit.
13. Take a walk together.
14. Bring along children or grandchildren and watch them play.
15. Bake simple recipes together.
16. Sit and hold the person's hand and lend a listening ear.
17. Bring a musical instrument that you play.

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)

David Stoyell, CRC Coordinator and Newsletter Editor

Telephone: (607) 274-5492

E-mail: dstoyell@tompkins-co.org

Caryn Bullis, Project CARE Coordinator

Telephone: (607) 274-5450

E-mail: cbullis@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.*

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

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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