



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 2016

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Caregivers Need to Be Listed on Medical Charts

Family caregivers provide a significant amount of non-acute nursing (home health) services as well as help with activities of daily living. A survey by the AARP Public Policy Institute and the United Hospital Fund found that 46 percent of family caregivers are "practicing without a license," performing such complex nursing tasks as wound care, injections and catheterization with minimal, if any, training. Sometimes doctors don't even know if their patients with chronic conditions have a caregiver. Even if they do know, many don't understand what those caregivers do. If the primary caregiver isn't also the next of kin, there most likely isn't even a record of his or her name.

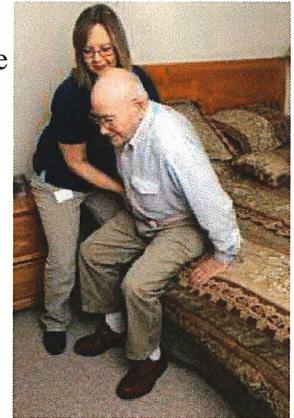
Recent legislation seeks to provide a partial response to this problem. The NY State CARE Act requires that family caregivers of patients be identified, informed, and receive necessary training in nursing tasks as part of the discharge planning process when their loved ones have been hospitalized or are being discharged from a nursing home to home. In 2013, Suzanne Mintz, founder of the *Caregiver Action Network*, asserted: "Until there is a place on medical records in every doctor's office to document a family caregiver:

--American health care will not be able to truly alter the way it provides care for those with chronic conditions,

--Family caregivers will continue to be relegated to the category of nuisance rather than taking their rightful place on the health care team as someone who has intimate knowledge of the patient that is not available to any other team member, and

--There will be no mandate for providing family caregivers with the education, training and support they need to be a more confident, capable care provider as well as a responsible steward of their own health.

Although there is a greater awareness of the problem today, we have a long way to go in acting on this knowledge.



Local Caregiver Support Services

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



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 Nicole Roustin, 279-5525.

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 Spouses Group

Meets monthly at the Office for the Aging. Call David Stoyell, 274-5492 for further information.

Protecting Elders from Financial Abuse

In the spring, many of us received unsolicited phone calls from scammers claiming to be from the IRS and threatening us with jail time if we ignored them. This summer, we may have contractors coming up to our door saying that they are working at a neighbor's house and can offer us a deal. In the fall, we may start getting unsolicited calls about health insurance.



All of these are illegal solicitations unless we have a previous business relationship with the firm. But they happen anyway and some of your elderly relatives may be vulnerable to such schemes. Other schemes include sweepstakes and prize offers, con artists steering seniors into high risk investments or pyramid schemes, and questionable fundraising tactics of some charities

Red Flags

Relatives, friends and other caregivers should be on the lookout for warning signs of fraud:

1. Piles of unsolicited mail from marketing and lottery operations.
2. High volume of packages containing inexpensive jewelry, watches, or other products.
3. Large number of magazine subscriptions.
4. High volume of unsolicited phone calls from marketers and others offering "valuable opportunities."
5. Large bank withdrawals for unexplainable expenses related to marketing companies and other businesses.
6. Does your relative (friend) seem to be unduly influenced by the advice of a particular person with whom you are not familiar?
7. Have your relatives' spending habits changed dramatically, or have they complained about

being short of money lately? Are utility and other bills not being paid?

8. Has your relative or friend switched health insurance in response to a marketer without getting information needed to make an informed decision about all their options?

Victimized by Relatives/Friends

Unfortunately, many vulnerable elders are being exploited financially by a relatives or "friends." Your relative may not ask for help. They may be in denial or ashamed of what has happened to them. They may fear retaliation or that they will lose needed help for their basic care. They may have a sense of misplaced loyalty to someone who has treated them well in other ways. They may be unable to report exploitation because of physical or mental incapacity. Any of the following changes can be signs of financial exploitation and should be treated seriously:



Changes in a person's demeanor

- New worry about their finances, especially missing funds
- Inability to remember making certain financial transactions
- Implausible explanations about what they are doing with their money
- Fears they will be institutionalized unless money is given to a particular person
- Afraid to answer questions in the presence of another

Questionable Transactions

- More frequent ATM transactions
- Large withdrawals from bank account
- Signatures on withdrawal forms that are suspicious
- Amounts and signatures that seem to be written with different pens

- New bank loans or debts

Suspicious Relationships with Caregivers

- New friends or relatives who are suddenly spending a lot of time with the person and appear too interested in their finances.
- The person is becoming increasingly isolated and overly dependent on a single relative, friend or professional caregiver.
- A caregiver who speaks for the person in a silencing way.
- The person seems nervous around, or afraid of, a particular relative, friend or caregiver.
- Someone inexplicably gains control over the person's finances.



If you suspect criminal activity, alert local law enforcement. Take definitive steps to prevent subsequent financial exploitation.

Social Security Email Scam

A fake Social Security email Scam is making the rounds.

The subject line reads:

“Get Protected.” The body of

The email invites you to sign up for a new service offering

credit report monitoring and promises to alert you about unauthorized use of your social security number. It's a phishing email to get you to click on a link that will then allow the scammer to install malware (like viruses and spyware) on your computer. Bottom line: if you get a questionable email, **do not click on any links.**



LOVE LIVING AT HOME

Love Living at Home (LLH) is a new nonprofit membership organization in Tompkins County dedicated to helping older adults live in their own homes, connected to their community, as long as possible. LLH follows a national model that seeks to improve access to services, increase socialization and civic engagement, and strengthen a sense of community among its participants.

“With one call to the office, LLH members will access a combination of volunteer assistance and community resources, as well as support in problem-solving for individual solutions. “We do not duplicate existing resources but help seniors move through the maze of options. Seniors living at home have peace of mind knowing one phone call can connect them to the support they need.”

“We organize programs to increase socialization and build community for members - thus helping create an independent, vibrant life filled with friends and meaningful activities. Members can meet for coffee and conversation, happy hours, walking tours and group cultural activities.”

“Members can also form groups to share common interests. Social events are planned by members for members. LLH is led by an engaged board and volunteer core of community leaders and supported by a professional staff and a host of volunteers. Volunteers are the glue that holds the Village together. Even with paid staff, volunteers represent most of the value provided to members.”

Volunteers will run some or all of the organization, oversee policy, serve on committees, and most importantly provide services to members. Annual membership dues are \$450 for an individual, \$575 for a household of two or more. To learn more about Love Living at Home, and how to become a member or volunteer, visit the LLH website: www.lovelivingathome.org or attend one of their upcoming public information sessions:

- **Saturday June 18, 10:00-11:30am**
Foundation of Light, 391 Turkey Hill Rd., Ithaca
- **Tuesday July 12, 6:30-8:00 pm**
Cayuga Medical Center (Howell Conference Room)
- **Saturday August 6, 10:00-11:30 am**
Lifelong, 119 W. Court St., Ithaca

Questions? Call 607-319-0162.

Caregiving and Career: Hard Choices

Many caregivers who have jobs and careers face some tough choices if they are considering leaving their jobs for a time or reducing their hours. As you face your decision, keep the following in mind:

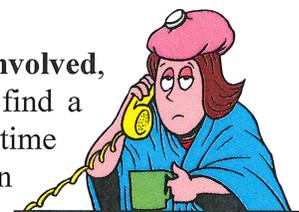
Points to consider

- **The budget needed to provide care at home in your absence.** Will you better meet the budget if you work and hire in-home care? Or quit your job to stay home and provide the care yourself? Your budget should also include regular breaks for you. If you stay home, budget an amount to spend on services weekly so you can take a break. If you continue to work, still budget an amount for regular breaks, whatever you feel you will need. Budget an amount that provides for a two-week annual vacation for you from caregiving—whether you stay home or continue to work.
- **Community services.** Are you taking advantage of all of the services available to your relative? Touch bases with your local Office for the Aging and/or go online to www.benefitscheckup.org to explore what services your aging relative may be eligible to receive: How would availability of services, services you were not aware of, impact your decision?
- **Your caregiving personality.** Will you manage at home, without heading out to the office every day? Or will you be miserable at work worrying about your mom? Would a part-time job affording you regular breaks from caregiving while pursuing a career work best?
- **Your future.** How will a loss of income affect your future?
- **Input of others.** Family members, friends, support groups members. What are their concerns, insights?
- **The length of time your care recipient may need your help.** Can you afford to stay home for two years? Five years? As long as

your care recipient needs you? In our most recent survey of family caregivers, almost 1/3 of respondents indicated that they expected their role as family caregiver to last another ten years. Would you be able to manage that long without a salary? With a full-time job?

As you know, chronic illness and disability can be deceiving; longevity often cannot be predicted. And there's no better cure than loving care from a family member. If you stay at home, be sure you understand how long you can manage without a salary. Start making plans now for when that time comes, when you need a salary. Which assisted living facilities, nursing homes and home health agencies are good in your area?

- **Your human resource department.** Does your company offer flex time? Sabbaticals? Telecommuting? Job sharing? Family & Medical Leave Act? What options does your employer offer? Would these options make caregiving and working easier?
- **Do you need a short period of time off from work, to find services, to hire in-home caregivers, to remodel your home?** Would taking such a leave make it possible for your home to accommodate your care recipient so that you can return to work full-time? Sometimes, we tend to view solutions as being all or nothing, but the best solution may exist somewhere in between.
- **Assistance of other family members and friends.** Would other relatives be willing to share the care, commit to a schedule of caregiving?
- **If you quit your job, what provisions will you make for your own medical insurance?** Will you have the insurance coverage necessary to ensure you stay healthy?
- **Sacrifices are always involved,** whether you stay at home, find a part-time job, or work a full-time job. Which sacrifices can you live with?



Getting the Most Out of A Family Meeting

(reprinted with permission from the Spring 2016 issue of the AFA Care Quarterly)

A family meeting is a specific time set aside to promote communication, decision-making, and problem-solving, and to encourage strong family relationships. When caring for someone with Alzheimer's disease or a related illness, family meetings are important in ensuring information is shared, putting care plans in place, and helping divide tasks among family members.

HERE ARE SOME TIPS AND STRATEGIES TO HELP PLAN A PRODUCTIVE FAMILY MEETING:

SET GOALS

- ✓ Set realistic and attainable goals for each meeting. Remember, the key objectives to a family meeting are to build consensus among family members and to align with one another for the betterment of a loved one's care.

PLANNING AND FOLLOW-UP:

Planning, coordination and follow-up are key to family meeting success. Here are some tips to help things flow smoothly:

- ✓ Include the individual with Alzheimer's disease if he or she is able to communicate preferences and has the ability to understand issues being discussed
- ✓ Determine all who are, or will, be part of the caregiving team (family, friend, professional) and make sure everyone is included in the meeting
- ✓ If family members are in different geographical areas, consider having the meeting via Skype, phone or video conference
- ✓ Set start and end times for the meeting and create an agenda ahead of time; encourage all family members to contribute ideas to the agenda
- ✓ To help keep meetings on track, limit topics to one or two
- ✓ Try to hold meetings regularly, and as needed, when there is change in your loved one's condition or care plan
- ✓ After each meeting, send a summary of decisions and agreements to all participants; Be sure to clearly define the responsibilities for each family member
- ✓ Create a family calendar, including medical appointments and activities, and each individual's responsibilities and commitments
- ✓ Consider using an outside facilitator, such as a social worker, clergy member or other professional to help guide the conversation and ensure everyone is heard

OTHER STRATEGIES FOR SUCCESS:

- ✓ Be prepared—bring information, such as doctor's notes and legal documents, to the meeting
- ✓ Assign roles—for example, choose one person as the speaker and one as record keeper
- ✓ Keep opinions out of the mix; stick to the facts of your loved one's care, such as a change in his or her physical abilities
- ✓ Use personal examples to illustrate points (e.g., "I have been present when mom has been up all night")
- ✓ If a family member is feeling angered or stressed, take a break to process these emotions
- ✓ Create a culture of respect and acceptance
- ✓ Acknowledge each member's strengths and try not to be judgmental of their limitations
- ✓ Collaboration and compromise are key: be mindful that there is no "right" way of being a care partner—we do things our way; others do it their way
- ✓ Not all issues regarding caregiving and decision-making will be 'solved' to your expectations; sometimes it is important to accept a solution that is "in the ballpark"



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Paying for Long Term Care

Long-term care involves a variety of services provided at home, in the community, and in facilities. These services include:

- ***Home-based care** such as home health aides,
- ***Community-based care** such as adult day care
- ***Facility-based care** such as assisted living and nursing homes.

Costs Can Be High

Long-term care can be expensive. Americans spend billions of dollars a year on various services. How people pay for long-term care depends on their financial situation and the kinds of services they use. Often, they rely on a variety of payment sources, including personal funds, government health insurance programs, such as Medicare and Medicaid, and private financing options, such as long-term care insurance.



The National Institute of Health has a good description of the ways people pay for long term on its *NIH SeniorHealth* pages found at: <http://nihseniorhealth.gov/longtermcare/payingforlongtermcare/01.html>

Following is a summary of the topics it covers:

Medicare Coverage - Medicare does not cover most long term care costs.

Medicaid – much broader coverage for people with very limited income and resources (or those who “spend down” to income eligibility levels).

Older Americans’ Act Programs- These include meals in the community and for homebound elderly, local transportation services, and limited in-home personal care and homemaker services for frail older adults.

Veterans Benefits- may help veterans with disabilities and their spouses pay for personal care and homemaker services provided at home.

Long Term Care Insurance – is a way of transferring much of the risk of needing expensive long term care to an insurance company. It is too late to purchase a policy if you already have a condition that makes it likely you will need long term care.

Private Financing Options

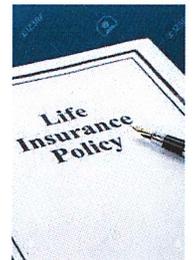
Paying from Savings and Annual Income- Some have enough income and resources to pay out-of-pocket for expensive long-term care

Most people don't have enough money to pay for all long-term care costs on their own, especially ongoing or expensive services like a nursing home. By planning ahead, they can use other private payment options. In addition to Long Term Care Insurance, these might include:

Reverse mortgages- involve borrowing against the equity in your home without having to make payments until you move from the home.

Life insurance or annuities that contain a long-term care rider

Life insurance settlements:
Accelerating death benefits to pay for care (reduces or eliminates death benefit payable to your beneficiary) or **Viatical Sales** of the policy to a third party.



Trusts- are legal entities that allows a person (the trustor) to transfer assets to another person (the trustee). The trustee manages and controls the assets for the trustor or for another beneficiary. Two types of trusts can help pay for long-term care services: **charitable remainder trusts and Medicaid disability trusts.**

Which private financing option is best for a person depends on many factors. These factors include the person's age, health status, personal finances, and risk of needing long-term care.

News and Notes

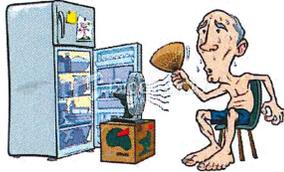
Now on Facebook

The Tompkins County Office for the Aging now has a Facebook presence. Visit our page and “like us” if you want to be kept up-to-date on programs and happenings of our office.



Cooling Assistance

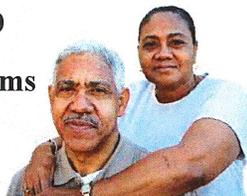
Older adults who are eligible for a heating assistance (HEAP) benefit in the winter are also eligible for cooling assistance if at least one member of the household has a medical condition exacerbated (made worse) by extreme heat. The medical condition must be clearly stated, documented in writing by a physician, physician's assistant, or nurse practitioner, and be dated within the last 12 months. HEAP Cooling Assistance was available beginning May 2, 2016. The program will close on August 31, 2016 or earlier, if funding is exhausted. Eligible households will receive installation of one (1) window air conditioner, or a portable air conditioning unit, if installation of a window unit is not feasible.



Other Financial Help

Help with Medicare Premiums

Medicare beneficiaries with income below \$1,357/month (individual) or \$1,823 (for a couple) can apply for an MSP (Medicare Savings Program) benefit. If approved, NY State will pay your Medicare Part B premium (currently \$104.90 for most). Your Medicare Drug or premium will also be paid for you up to \$39.73/month and you will automatically qualify for reduced co-pays at the pharmacy.



Farmers' Market Coupons

The New York State Farmers Market Nutrition Program provides coupons for low-income seniors. Eligible seniors (60+) can pick them up

at the Office for the Aging starting in late June. The coupons can be exchanged for locally grown fruit and vegetables at participating farmers markets in New York City. To be eligible, one must be at least 60 years of age and have income less than \$1,832 per month (for household of 1) or \$2,470 (for household of 2). Each person in the household who is 60 or older can pick up their own coupon book.

Basic Phone or Cell Phone Service

Seniors eligible for HEAP are also eligible for “Lifeline” discounted phone service. This can come as a discount on your landline (applied for through your phone service).



Alternatively, eligible individuals can apply for a free cell phone which comes with a monthly allotment of free minutes for calls and free texting. To apply for the cell phone, search online for providers such as Assurance Wireless, Safelink Wireless or Reachout Wireless or call the Office for the Aging for assistance if you don't have computer access.

Fall “Powerful Tools” Classes

This fall, we will be able to offer our popular “Powerful Tools for Caregivers” classes at different times of days and different locations throughout the county. They will begin toward the end of September and these 90 minutes classes will be held weekly for six consecutive weeks. Exact times and locations were not available at the time of this printing. If you want to be notified about the dates/locations when they are finalized, please email dstoyell@tompkins-co.org to express your interest or call David Stoyell at 274-5492. If there is a day or week or time of day that is better for you, please also let us know that. Otherwise, the fall program dates will be publicized in the fall issue of this newsletter to be sent at the end of August.



Alzheimer's Page

Project Lifesaver

The implementation of Project Lifesaver was inspired by the loss of our 81 year old Tompkins County resident, Johanna Kirkwood. She wandered away from her home in Lansing, N.Y. on March 3, 2012 and was found deceased not too far away. Johanna suffered from Alzheimer's.



Project Lifesaver may make a difference by assisting law enforcement with the timely recovery of a missing person.

How Project Lifesaver Works

1. Each participant is fitted with a personalized Project Lifesaver wristband. This unique wristband is a one ounce, battery operated transmitter that emits an automatic tracking signal every second, 24 hours a day.
2. The signal can be tracked by trained personnel from the Sheriff's Office using patrol cars and on foot using hand-held equipment; which uses radio frequency for the tracking capability.
3. When necessary, a helicopter, equipped with radio frequency tracking capabilities can be used in the search, in conjunction with the Onondaga County Sheriff Department Project Lifesaver.

Program Fees

In order to learn more information about the cost of the program, please contact the T.C. Sheriff's Office (607) 257-1345, ext. 455. They will be happy to talk with you more about the program. There is a deposit of \$300.00 for the equipment; which is refunded at the time that the equipment is returned undamaged. There is a non-refundable \$10.00 charge collected every 60 days for replacement of batteries and bracelet straps. Donations help extend the program to those who cannot afford these fees.

Six Things to Know about Someone with Dementia

I can still smell the flowers.

I don't garden anymore, but I can still smell the flowers. Bring me some roses. This will remind me of my past.

I can still communicate.

I can't talk the way I used to, but I can still communicate. Be patient as I try. This will help me feel connected.

I can still make decisions.

I don't have the judgment I used to, but I can still make decisions. Give me choices. This will make me feel like I'm a part of things.

I can still wash my face.

I can't take a bath by myself anymore, but I can still wash my face. Assist me with direction. This will help me feel purpose.

I can still sing.

I can't dance anymore, but I can still sing. Help me enjoy music. This will enrich my life.

I can still move my body.

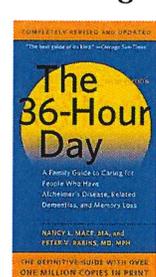
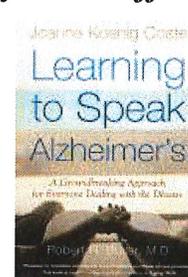
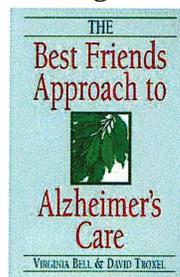
I can't walk unassisted anymore, but I can still move my body. Walk with me, and support me if I stumble. This will help me feel engaged.

You are my lifeline. I depend on you. But please don't do for me what I can do for myself.

Recognize what I can do and help me to function as a person. You are key to the quality of my life.

(by Dan Lonigro, CPI Global Instructor, reprinted with permission from the website of CPI, www.crisisprevention.com, offering training and consulting in behavior management/dementia care.)

Look for these and other books on caring for a loved one who has dementia in the **Lending Library at the Office for the Aging:**



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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Telephone: (607) 274-5491

E-mail: kschickel@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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