



In Support of Caregivers

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

Winter 2011-12

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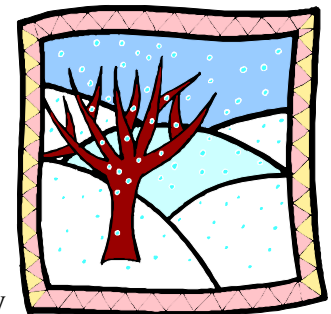
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New Weekly Group Format Proves Successful

Dear Readers,

This fall, the Caregiver Support Group (CSG) has enjoyed success in its switch of format from a monthly to a weekly group, significantly increasing its attendance from previous years in the process. The group has welcomed a special guest the first Thursday of each month: in November, Nick Boyar, mindfulness expert, discussed the benefits of mindfulness practice and how those benefits can be utilized in caregiving; and in December, Linda Holzbaur, discussed the similarities and differences of parental and spousal caregiving. Both guests prompted fascinating discussion and inspired mutual aid amongst group members.

The CSG plans on building on its successes in the coming new year. It already has special guests planned for the first Thursdays in February and March. On February 2, Patricia Brehl, Binghamton graduate student in social work, will introduce her work in art-therapy to the group and do a demonstration in how caregivers can use the arts to help with their self-care in her presentation of Art Therapy for Caregivers. On March 1, Ithaca College Professor and published poet, Jerry Mirskin, will discuss Poetry & Caregiving: How Writing & Reading Can Help Caregivers.



The group will take a holiday break for two weeks with no meeting scheduled for December 22 and 29. The group will start up with weekly meetings beginning again on Thursday, January 5 (at Lifelong beginning at 6:30 PM).

Winter Support Groups

The Caregivers' Resource Center facilitates the following groups. Call 274-5492 for details.



Weekly Caregiver Support Group Meeting

- Open to those caring for parents, spouses or other elderly relatives or friends.
- **Every Thursday at 6:30 PM.**
(No meeting on December 22 and 29. Weekly meetings resume on January 5.)
- Meets in the lounge at Lifelong, 119 W. Court St., Ithaca

Alzheimer's Support Group

- Open to those caring for loved ones with Alzheimer's or other cognitive impairments
- **Generally meets the 4th Tuesday of month:**
(Note: the December meeting will be held a week early, on Tuesday, Dec. 20.)
- 1:00 - 2:30 PM in the Office for the Aging Conference Room (320 N. Tioga St., Ithaca) in the main courthouse.

Parkinson's Support Group

- Open to Parkinsonians and their Caregivers.
- Meets Quarterly: (Next Meeting: **January 17**)
- 2:00 PM - 3:30 PM at Cooperative Extension, 615 Willow Ave., Ithaca

Other Alzheimer's Groups

In addition to the Tompkins County Alzheimer's group (above), the following meeting may be convenient for those caring for loved ones with Alzheimer's or a related disorder:

3rd Wednesday of the Month, 12:30-1:30 PM, Walden Place, Cortlandville. Includes free light lunch and companion care is available. Call for reservations, 756-8101.

Local Caregiver Services

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging

David Stoyell, Katrina Schickel, Robert Levine
(274-5482)

**Discover the
Resource Center**

The Caregivers' Resource Center & Alzheimer's Support Unit offers family caregivers information and consultation services, support groups, workshops, this newsletter, and a lending library of books and videos on caregiving topics. Stop by or call for an appointment.

Volunteers from *Project CARE* give 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.

In-Home Counseling & Respite Service

Family and Children's Service

Jessica Gosa (273-7495)



A caregiver counselor will meet with family caregivers at their home, her office, or elsewhere and help them work through complex caregiving issues or for emotional support. This program also offers grant-funded respite aide service to give caregivers a needed break.

Adult Day Program

Longview Adult Day Community

Tuesdays, Wednesdays, Thursdays,
9 AM- 3 PM

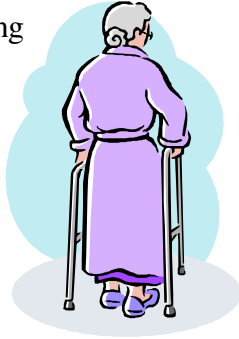
Pamela Nardi (375-6323)



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. Includes lunch and snacks.

A Proactive Approach to Caregiving

Instead of waiting for a crisis to spur us into action, a more proactive approach to family caregiving usually works out better in the long run. How do we prepare ahead of time to meet care needs of loved ones?



Where to Begin

- Start with inviting your parent or other relative to communicate his/her wishes and fears to you before expressing your concerns. This is key. Just to say “we want what’s best for you” may sound a little hollow to a parent who thinks you don’t really know what’s important to them and how they feel.
- Being alone in one’s home is not necessarily a healthy choice. If you understand that a widowed parent needs and wants to be as autonomous as possible while still meeting their need and desire for companionship and support, you will be better able to support them when they are faced with difficult choices.
- Do get around to addressing the tough topics in your conversation: health status, money, driving, long term care options, preparation of advance directives for end of life care and other surrogate decision-making (health care proxy and power of attorney) that may be needed.

Assessment

- Observe and discuss changes in behavior, mood, and cognitive or functional impairment.
- Get a complete medical diagnosis.
- Gather information on medication regime. Make sure there is an organized file of important papers, health and insurance premiums, and other bills to keep paid up, etc.

Learn about Resources

- The care of older adults can indeed “take a village”: family, health care professionals, elder care professionals, geriatric care managers,

especially if family caregivers live at a great distance from loved ones.

- Learn about options for paid care when needed (home care, assisted living, day programs, continuing care communities) and the reputation for each provider in the community for delivering quality care.
- Think about home modifications and assistive equipment that might enable your loved ones to remain as independent for as long as possible despite increasing frailty.

Communication with Other Family Members

- Talk with other family members before the crisis. Advance communication and research can better position families to quickly get on the same page if a crisis does occur. They then can decide how tasks and responsibilities will be divided and develop an ongoing communication strategy.
- If family members have significant conflict about caregiving, consider local mediation services when the need arises.



Avoid Teaching Helplessness

When you are pressed for time, waiting for your mother to brush her hair and put on a sweater seems to take forever. Brushing her hair and putting her sweater on for her is much faster. Over time, though, she will begin to believe that she is helpless...and to need more and more help.

"Learned helplessness" occurs when we always do things for or make decisions for people, instead of letting them do it themselves. Over time, people come to believe that they are not capable of doing anything for themselves. Sometimes, of course, it is faster to "do it for" someone than to wait for them to do it themselves. People with disabilities do need certain kinds of help, but teaching people to be helpless costs the caregiver and the care receiver in the long run.

Caregivers Can Help Prevent Falls

“Falling is simply **NOT** a part of growing older”
-Betty Perkins-Carpenter, Ph.D.

Although one out of three people over 65 fall each year and one in ten falls result in hospitalization, family caregivers can help older adults control their risk of falling.

Anyone who has fallen in the past year, or who is unsteady on their feet, or is afraid of falling, is at higher risk of falls.

Three Steps to Reduce the Risk of Falling:

1. Talk to Health Care Providers

Any of the following medical conditions can increase the risk of falls. You or your loved one may want to talk to the doctor or physical therapist about treatment and coping strategies if any of the following common conditions are increasing their risk of falls:

- Vision problems
- Joint/muscle weakness
- Arthritis
- Foot problems/improper footwear
- Dizziness when you change positions
- Osteoporosis
- Medication side-effects
- Incontinence
- Neurological problems

Also, you can check with your pharmacist to find out if medications are making your care receiver weak or dizzy.

2. Practice Strength & Balance Exercises

People sometimes avoid exercise because they are frail or afraid that activity will increase their risk of falling. You are less likely to fall if your muscles and bones are stronger. Exercises can also improve your coordination and flexibility. If someone is avoiding exercise because of the fear of falling, let the doctor know so he/she can recommend a program or make a referral to a physical therapist who can devise a custom exercise program.

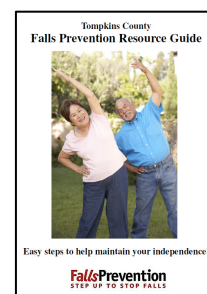
There are many group exercise programs as well as programs for use in the home that are tailored to older adults, including programs for those who need to do most or all of their exercises while sitting. A list of “Strength and Balance Programs” available locally is in the new *Tompkins County Falls Prevention Resource Guide* (pp. 7-12). It can be view online at www.tompkins-co.org/cofa or obtained from the *Tompkins County Office for the Aging* (274-5492). The guide also illustrates sample exercises.

3. Make Your Home Safer

Most falls occur in or around the home. Remove hazards from your home, make necessary repairs or modifications, light up your living space and use properly-fitted assistive devices. Checklists and other tools for assessing a home for fall hazards are available in the *Tompkins County Falls Prevention Resource Guide* (pp. 13, 22-25).

Other resources in this new resource guide include:

- **Home Modification Resources**- getting a professional assessment done, tips for finding a contractor to do the modifications/repairs
- **Help for low-income households** with home modifications
- **Assistive Equipment** that can reduce the risk of falls and where you can borrow, rent or purchase it.



Free Exercise DVD

A free DVD is available from the Office for the Aging that focuses on two forms of exercise:

1. **Tai Chi** (“how to” and easy-to-follow exercise routines)
2. **Strength Exercise Routines**
(choice of three levels of intensity.)

Winter Presentations of Interest to Family Caregivers

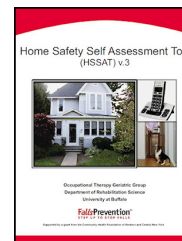
January Workshops

(These workshops are free and will be presented at the Finger Lakes Independence Center, 215 Fifth St., Ithaca. Call Teri (272-2433) or email flicadv@hotmail.com for more information or to register for one or more workshops.)

January 11: 1:00-2:00pm

Introduction to the Home Safety Self-Assessment Tool with Teri Reinemann, Systems Advocate at Finger Lakes Independence Center

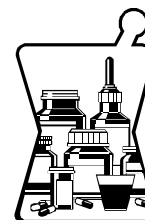
Get your free room by room guide for conducting your own home safety inspection. Learn how to identify home hazards and make corrections. The 48-page booklet also contains tips for preventing falls, as well as local resources for finding durable medical equipment and home repair assistance programs.



January 18: 1:00-2:00pm

Managing Your Medication to Stay Independent with Rachael Hutchinson, Pharmacist at Cayuga Medical Center

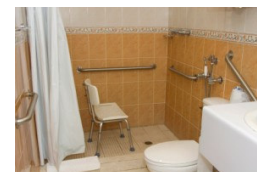
Medications are an important and a necessary part of treating an illness and/or managing a chronic disease. But for some people, different medications can lead to drowsiness, dizziness or feeling lightheaded; all of which can affect your balance and increase your risk of falling. Learn how to develop strategies for proper use of your medications and tips for talking with your pharmacist or other healthcare provider.



January 25: 1:00-2:00pm

Designing for Change: An Adaptable Home for Aging in Place with Scott Jones, Lead Accessibility Consultant at Empowerment by Design

One of the most important ways to ensure people can remain at home for a lifetime is to create an environment that promotes ease of access and use. In this session, Mr. Jones will discuss home accessibility principles and provide practical tips for creating cost effective home adaptations to promote safety and independence.



Caregiver Support Group Presentations

(These presentations are offered at 6:30 PM at Lifelong, 119 W. Court St. prior to the regular weekly support group meeting. All are welcome for the presentation. Only family caregivers can remain for the support group meeting that follows.)



Thursday, February 2

Art Therapy for Caregivers

with Patricia Brehl, Binghamton graduate student in social work

A demonstration in how caregivers can use the arts to help with their self-care.



Thursday, March 1

Poetry & Caregiving

with Jerry Mirskin, Ithaca College Professor and published poet

Discussion of how writing & reading can help caregivers.

Veterans Benefits and Aging

Most veterans (about 78%) of military service in New York State are over the age of 50. About 30% of veterans access VA health care benefits.

Some VA health care benefits

Preventative: Immunizations, physicals, screenings, health education program.

Pharmacy: Veterans can get their medications through the VA. If they do, there is no need for a veteran to enroll in Medicare Part D. Veterans do not need to stop going to a private physician. The VA will coordinate care with their private physician. Veterans who are signed up for VA pharmacy program are considered by Medicare to have “creditable coverage.” Thus, they are not subject to a late enrollment penalty if they ever want to sign up for Medicare D. Veterans who receive Medicare may want to sign up for the pharmacy program even if they don’t use the benefit so they have “creditable coverage.”



Outpatient Care: medical, surgical, mental health, substance abuse.

VA nursing home care- long-term nursing home care only is open to those who are 70% service-disabled or those who are hospice-eligible (have a 6 months prognosis). Short-term respite stays may be possible for other veterans in VA facilities or at residential care facilities that have a contract with the VA.

Home Health Care – for veterans who have significant long-term care needs. To apply for in-home supportive services, the VA Primary Health Care Team (social worker and nurse) must authorize supportive services (such as respite, home care, transportation, adult day programs, etc.) after determining the veteran

has significant care needs that meet the disability criteria. If an application is denied, an

application can be resubmitted and approved if additional disabilities can be shown (e.g., showing hearing loss since first application).

Aid and Assistance Benefit

Veterans who served in wartime who have significant care needs (requiring the regular assistance of another person to perform everyday functions) may be eligible for the “Aid and Assistance” pension benefit if they meet the income test and have assets valued at \$80,000 or less (not counting home, auto). Although many make too much to be eligible for this benefit, many veterans do become eligible if they begin to have high out-of-pocket expenses for home care or assisted living facility charges.

For example, someone with a household income of \$4,500/month makes far too much to be eligible for this VA pension. However if that same individual has to begin paying \$4,500/month for home care aide service or assisted living services at a residence like



Longview or Clare Bridge, that charge will be deductible from their income along with other un-reimbursed medical expenses and may make him/her eligible for this VA benefit (of up to \$19,736 for a single individual or \$23,396, if married).

Each county in New York State has a VSO (Veteran’s Service Office) that veterans or their caregivers can call to discuss eligibility for VA benefits and how to access them. In Tompkins County, call the **Veterans’ Counseling Center at 272-1084**. The VA also has a national **Caregiver Support Line: 1-855-260-3274** which you can call whether you need immediate assistance or have questions for the licensed professionals who answer the calls.

Managing Incontinence

Some of our readers are providing care to loved ones who need assistance with personal care and hygiene. Incontinence can be one of the more challenging aspects of caregiving. In a recent webinar sponsored by *Today's Caregiver and TotalHomeCareSupplies.com*, Michele Mongillo, RN, asserts that while incontinence can be managed, it does not need to manage you. Following are some notes from the webinar. If you are dealing with incontinence now, you may want to view the entire 1-hour webinar at www.caregiver.com. (Click on *Incontinence Webinar* in the "Features" section.)

Many of our loved ones can manage their own incontinence, but if they need you help:

Establishing a schedule- is crucial to managing incontinence rather than it managing you.



"I don't need to go." Avoid trying to get them to go at random times and quizzing them about whether or not they have done. Praise/positive reinforcement is important when they cooperative with the schedule (without using language or a tone that makes them feel treated like a child).

Dementia and incontinence- Individuals with impaired cognition can also follow a schedule with assistance. Setting alarm? Developing other prompt/cue. Clothing: no buttons, zippers.

Skin health. Essential to cleanse after each episode. Never use soap and water and don't use baby wipes; use adult wipes to avoid or protect impaired skin. Consider incontinence cleaners. Use clear ointment that is moisture repellent (like aloe vera) rather than a product like Desitin that is hard to clean off. "Clean, repair, protect."

For Cleaning/Cutting Odor – 1 part vinegar to

2 parts water as a cleaning solution. Put vinegar mix in a spray bottle. Stay away from flowery fragrances-they only cover up odor.

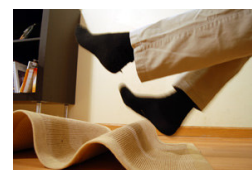
How often to check/change? Will vary. Important thing is to set schedule. Skin will be OK until you get to them if using a good product.

Resists using incontinence products. Use adult pull-ups that feel more like regular underwear and that don't have tabs. Seems more normal. There are products made for men that don't look like diaper or female underwear (that are very thin, not bulky.)

How to stop Dad from taking off pull-ups at night. Use nighttime products or a different product that might not be irritating him or put underwear over the products. Avoid plastic products or doubling up of products (that will hold in heat.)

Can products be covered by Medicare? No, unless provided by a certified Home Health Care Agency or Hospice.

Environmental changes. Clear path to the bathroom. Make modifications to prevent falls while hurrying to bathroom (remove clutter, throw rugs, rails on bed, grab bars in bathroom, proper lighting).



Nighttime- In addition to toileting just before going to bed, limit fluid intake 2 hours before. Consider bedside commodes and/or night-time products.

For more information on Today's Caregiver magazine, go online to www.caregiver.com or call 1-800-829-2734. You can also sign up for their free weekly caregiver newsletter on their website and/or read articles on a variety of topics of interest to family caregivers.

Getting Sibling Help with Caregiving

Q: *My siblings are of little help to me in taking care of our father, who has Alzheimer's. We all live in the same town. How can I get more help – even just moral support or an occasional visit – from them?*

A: Issues between siblings in caregiving families are one of the most common concerns...Family dynamics and sibling roles are emphasized in any family crisis or stressful situation. Facing the long-term care of a family member is indeed a family crisis.

It is really important to recognize that individuals react to stressors in many different ways. The sibling who is most likely to take on the primary caregiving role can often look back over time and see that he or she tends to respond by mobilizing resources and taking a "hands-on" approach to managing difficult situations.

Others may not be as comfortable with the same level of involvement. Tasks that can be accomplished from a distance and require less emotional or "hands on" involvement may appeal more to these family members. In fact, they may be willing -- if not relieved -- to be given an assignment or a list of tasks, e.g., "I need you to drive Dad to the doctor on Thursday," or "Please pick up this prescription tomorrow." Others may be able to contribute financially, if not emotionally.

Many successful caregiving families report that they have divided up the responsibilities according to individual preferences and capacity. This way, everyone feels that they are contributing and the burden for the primary caregiver is significantly lightened. A family meeting can often accomplish these kinds of agreements...

Other siblings may become withdrawn and prefer not to be involved at all. This can cause great resentment from the more active participants. However, it appears that those who

prefer no involvement are often still carrying unresolved family issues, which only they can work through themselves.

When it begins to feel like your burden is increased due to others' non-participation, ask for specific kinds of help that these individuals would be able to provide. Asking for help directly may give the individual an opportunity to offer what they can. If the answer is "no," then it is time to remind yourself to let go of what you cannot change and work with the resources that are available to you.

In many communities, resources – such as adult day care centers or "friendly visitor" programs – are already in place to assist caregivers, even if siblings are not being very supportive. We encourage you to research services available in your community.

(Used with permission of Family Caregiver Alliance, National Center on Caregiving. For more information and to view a fact sheet on "Caregiving with Your Siblings," visit www.caregiver.org or call (800) 445-8106.)

New in the Lending Library

The following books may be of particular interest to those caring for loved ones with Alzheimer's or related disorders. They are available for loan along with many books of interest to family caregivers in the lending library of the Caregivers' Resource Center at the Office for the Aging.



Forget Memory: Creating Better Lives for People with Dementia, Anne Davis. Johns Hopkins University Press. 2009.

The director of the Center on Age and Community at the University of Wisconsin offers a critique of our culture's one-dimensional view of dementia and a vision for how we can change the way we think about and care for people with memory loss.

Living Your Best with Early-Stage Alzheimer's, Lisa Snyder, Sunrise River Press. 2010.

The director of the Quality of Life programs at the Univ. of California at San Diego offers a practical guide for people with early-stage dementia full of answers and solutions to day-to-day questions and challenges.

Still Alice, Lisa Genova, Gallery Books. 2007. (Audiobook available from Simon and Schuster.)

The award-winning first novel by a neuroscientist from Harvard. A moving and depiction of life with early onset Alzheimer's (onset around age 50).

Sometimes Overlooked Benefits

EPIC – The New York State Elderly Pharmaceutical Insurance Coverage (EPIC) program continues to pay the Medicare D premium (up to \$39.79/month) for individuals age 65 and older who make under \$23,000/year or for couples who make under \$29,000/year.

As of January, 2012 EPIC will help individuals with income under \$35,000/year (or couples under \$50,000/year) pay most of their prescription co-pays only if they fall into the coverage gap (“Donut hole”).

HEAP- Help with paying the heating bill is available to those with total household income under \$2,146/month for 1, \$2,806 for 2, (higher amounts with larger household size).

Medicare Savings Program- Individuals with net income under \$1,246/month can apply to have Medicaid pay their Medicare B premium for them (a \$99.90/month savings for most people this year). Other health insurance premiums (Medigap, Medicare Advantage or Medicare D premiums) are deducted from total income in determining net income.

If you or your loved one desire further information on any of above benefits or applications, call the Office for the Aging, 274-5492.



What Family Caregivers Do

Family caregivers serve numerous roles:

- Provide companionship and emotional support
- Identify and coordinate services and supports
- Provide transportation to medical appointments and community services
- Serve as “advocate” for loved ones during medical appointments or hospitalizations

Some also:

- Handle bills; deal with insurance claims
- Communicate with health professionals
- Play a key role of “care coordinator” during transitions, especially from hospital to home



Other caregivers:

- Help with household tasks, such as preparing meals
- Hire and supervise direct care workers
- Implement care plans

For some, caregiving has progressed to:

- Carrying out personal care, such as bathing and dressing,
- Being responsible for nursing procedures in the home,
- Administering and managing multiple medications; sometimes injections.

“A key theme to emerge from systematic reviews of family caregiving studies over the past 30 years is that family care can have negative effects on caregivers’ own financial situation, retirement security, physical and emotional health, social networks, careers and the ability to keep their loved one at home. This impact is particularly severe for caregivers of individuals who have complex chronic health conditions and both functional and cognitive impairments.” (*Valuing the Invaluable. 2011 Update. AARP.*)

Call us at the Caregivers Resource Center to discuss your own challenges with balancing self-care with caring for a loved one (274-5492).

The Caregivers' Resource Center and Alzheimer's Support Unit

Please call or visit us at the Tompkins County Office for the Aging in the County Courthouse basement, 320 North Tioga St., 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.tompkins-co.org/cofa

Click on "Gateway to Senior Services" at the top of the home page to access our Tompkins County resource guides and as well as back issues of this newsletter.

Family Caregiver Alliance: www.caregiver.org

Next Step in Care: www.nextstepincare.org

National Alzheimer's Association: www.alz.org

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