



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 2012

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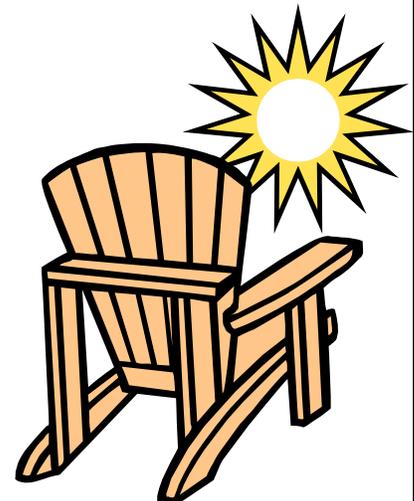
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The Caregivers' Resource Center

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
- Lending library of books and videos on caregiving topics
- Speakers available to talk to community and employee groups on caregiving topics



*These publications are also available on-line at: www.tompkins-co.org/COFA

(Click on "Local Resources for Older Adults" or "Newsletters")

Summer Support Groups

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



Bi-weekly Caregiver Support Group Meeting

- Open to those caring for parents, spouses or other elderly relatives or friends.
- **1st & 3rd Thursday of each month: 6:30 PM**
- 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
- **Meets the 4th Tuesday of each month (July 24, Aug. 28, Sept. 25)**
- 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: July 18**
- 2:00 PM - 3:30 PM at Cooperative Extension, 615 Willow Ave., Ithaca

Evening Alzheimer's Group

In addition to the daytime group (above), people caring for loved ones with Alzheimer's or related disorders can also attend a group that meets at 6:00 PM on the 1st Wednesday of each month at Lifelong, 119 W. Court St.. Because of the holiday, the July meeting will be held on Wed., July 11. For information, call the Alzheimer's Association at 785-7852 ext. 119.

Local Caregiver Services

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging
David Stoyell, Katrina Schickel (274-5482)

The Caregivers' Resource Center & Alzheimer's **Discover the Resource Center**

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.

When New Symptoms Appear: Disease or Drug?

New symptoms in older adults require healthcare providers to consider all possible causes—including medications.

Diligence in analyzing medications is necessary to avoid “prescribing cascades.” A **prescribing cascade** occurs when the adverse effect of a drug is misinterpreted as a symptom or sign of a new disorder and a new drug is prescribed to treat it. The new, unnecessary drug may cause additional adverse effects, which may then be misinterpreted as yet another disorder and treated unnecessarily, and so on. Unfortunately, adverse drug effects often go undetected and lead to unnecessary injury, compromised quality of

life, and increased cost and use of healthcare resources. Following is a chart listing commonly overlooked adverse effects in older adults (*appearing in the Winter 2011-2012 issue of Generations, Vol. 24, Number 4, Amber N, McLendon and Penny S. Shelton, Journal of American Society on Aging*).

A six-page consumer guide, “Managing Multiple Medications in Later Life,” can be viewed on the website of the Tompkins County Office for the Aging at www.tompkins-co.org/cofa/. Click on “Local Resources for Older Adults” and then “Medications Guide.”

Drug or Drug Class	Commonly Overlooked Adverse Effect(s)
Alpha blockers (e.g., alfuzosin, tamsulosin)	Urinary incontinence
Amiodarone	Thyroid disorders
ACE Inhibitors (e.g., lisinopril, enalapril, ramapril)	Cough
Anticholinergics (e.g., amantadine, scopolamine, benztropine)	Blurred vision, dry mouth, constipation, urinary retention, confusion
Anticonvulsants (e.g., divalproex, olanzapine)	Osteoporosis, folate deficiency
Aspirin	Tinnitus
Antipsychotics (e.g., risperidone, olanzapine)	Movement disorders, high blood glucose, low BP, high cholesterol, weight gain
Bisphosphonates (e.g., alendronate, ibandronate)	Blurred vision
Bupropion	Seizures
Caffeine and/or nicotine	Elevated blood pressure or heart rate
Calcium channel blockers (e.g., amlodipine, diltiazem)	Gastroesophageal reflux, constipation, edema
Cholinergic Agents (e.g., bethanechol, pilocarpine)	Urinary incontinence
Cholinesterase Inhibitors (e.g., donepezil, rivastigmine)	Urinary incontinence
Corticosteroids (hydrocortisone, prednisone)	Cataracts, glaucoma, gastrointestinal bleeding, high blood glucose, osteoporosis, skin atrophy
Histamine-2 agonists (ranitidine, famotidine)	Vitamin B12 deficiency
Inhaled corticosteroids (budesonide, fluticasone)	Hoarseness, sore throat, thrush
Cox-II inhibitors	Edema, heart failure
Levodopa	Low blood pressure
Metformin	Diarrhea, edema, heart failure, low BP, nausea, vitamin B12 deficiency
Methotrexate	Folate deficiency
Metoclopramide	Movement disorders
Non-steroidal inflammatory drugs (ibuprofen, naproxen)	High BP, decreased kidney function
Potassium supplements	Esophageal or gastrointestinal irritation or ulceration
Proton pump inhibitors (e.g., omeprazole, pantoprazole)	Diarrhea, vitamin B12 deficiency
Pseudoephedrine	Urinary incontinence in men with enlarged prostate
SSRI's (sertraline, citalopram)	Falls
Statins (simvastatin, atorvastatin)	Muscle pain or weakness
Thiazide diuretics (e.g., hydrochlorothiazide)	Gout
Thiazolidinediones (TZDs) (e.g., pioglitazone)	Edema, heart failure
Venlafaxine	High blood pressure

Mindfulness Exercise: Three Minute Breathing Space

The purpose of the 3-minute breathing space is to help you step out of automatic pilot and access a clearer state of mind instead of reacting mindlessly to the negative thoughts created by your mind. This exercise can help you slow down so you can respond more skillfully to stressful situations and use different approaches to relate to your thoughts. Remember the goal of this exercise isn't to take away negative feelings.

Three Minute Breathing Space

Step 1: Awareness

Sit upright in a comfortable position and close your eyes.

Start by bringing your awareness to your inner experience. Just observe:

What bodily sensations are present?

What thoughts are going through my mind?

What feelings do I have?

(The goal is for you to be a quiet observer, just noticing what you're experiencing. If you are becoming entangled with thoughts and worries, gently come back to a simple awareness of what you are experiencing, without judgment or trying to change anything.)

Step 2: Gathering

Next gently redirect your attention to the physical sensations of your breath. Follow the breath all the way in and all the way out. Notice the sensations and movement in your belly. Use your breath to anchor yourself to the present.

Step 3: Expanding

Now expand the field of your awareness around your breathing so that it includes a sense of your body as a whole. If you sense tension or discomfort, breathe into it as you soften and open. On the out-breath, you can say, "It's okay...whatever it is, it's already here. Let me feel it."

Do this practice at any time in the day, or night, when you feel you could benefit from feeling more grounded and relaxed.

New York's Caregivers

With more than 3 million unpaid caregivers, NY State ranks third in the nation in the number of informal caregivers. About 80% of community-based long term care is provided by family or other informal (unpaid) caregivers.



Without caregiver support, the NY State Office for the Aging has estimated that 50% of older residents receiving care would have to be placed in residential care settings.

Transportation Survey

Help us improve transportation options here in Tompkins County. Local transportation partners are working with a national transportation innovator (ITNAmerica), to research new ideas in community transportation which would build on existing services to offer new ways of providing and organizing personal transportation.

These could include a volunteer ride service for seniors or others, people sharing rides in private vehicles, people riding together in vans. You can help by completing an online survey. Think not only of your care receiver's situation, but what you yourself might appreciate at some point in the future.



To take the survey, go online to:

surveymonkey.com/s/itnetompkins

(Plan on it taking 15-20 minutes to complete.)

Telephone Reassurance Calls

Telephone Reassurance subscription services call individuals on a daily basis to check on their well-being.

A local caregiver called recently to say how pleased she was with the national service to which she subscribed (CallingCare.com). She described its website as easy to navigate and the service easy to set up.



CallingCare is an automated system that will call your loved one daily, based on the calling schedule you provide. After hearing a message you've chosen, your loved one will be asked to "Press 1" if he/she is OK or to "Press 3" if he/she needs help.

If the system is unable to reach your loved one after a series of three back-to-back calls, or he or she indicates to the system that he or she needs help, the system will call you immediately to let you know what is happening, and will call several times until you acknowledge receiving the notification. The system can also notify an additional backup phone number, as well as send out notification emails.

The message can be customized (for example, including a reminder to take a medication). An answering machine does not need to be turned off for this system to work as it is able to distinguish between a person answering the phone and a call being picked up by an answering machine.

The basic service costs as little as \$14.95/month. A trial 2-week subscription costs \$5.00. Learn more at www.callingcare.com or call 602-265-5968 (ext. 7).

Prolonged Illness & Grieving

Thanks to advances in diagnosis and treatment, people are living longer with life-threatening illnesses, such as cancer and heart disease. A new book available in the lending library at the Office for the Aging suggests that this changing reality affects the grieving process as well.

In *Saying Goodbye: How Families Can Find Renewal Through Loss*, Barbara Okun, a psychologist at Harvard Medical School, and psychologist Joseph Nowinski, identify a pattern of grief commonly encountered by families who face the loss of a loved one to protracted illness. It includes the following stages:

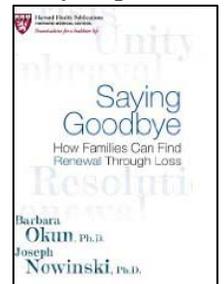
Crisis. Family life is disrupted by the diagnosis. People are upset, saddened and anxious. Other, unexpected feelings—resentment, anger, guilt—may also emerge but often go unexpressed in the interest of rallying around the patient.

Unity. The patient's needs are paramount. Okun says, "This is when everyone is on the same page: what can we do to help?"—like managing medical treatment, lining up social and support services, gathering insurance and other information, and attending to legal matters.

Upheaval. The patient may be in remission or doing relatively well. But for others, unity and patience may have worn thin as protracted illness buffets their lives and relationships. It's important now for family members to communicate honestly about the upheaval they are experiencing.

Resolution. As patient health deteriorates, everyone comes to accept that end of life is near. Decisions about hospice and other end-of-life matters have been made. Now is the chance for resolving old issues, healing wounds, and addressing resentments and jealousies.

Renewal. This final stage begins with the funeral and continues for a long time, as individuals adjust to the loss and to their changed roles.



Danger Signals: "Warning: Caregiver Needs Help!"

When is it okay to cry “uncle?” To say, “I can’t give any more unless I get some help.” Many caregivers trudge on under unbearable conditions rather than “admit to such failure.” What happens, though, is their own health suffers more and more, and eventually they themselves need care. Others simply don’t realize they’re taking on too much until it’s too late.

If you notice any of the following danger signals, you are probably approaching role overload and should seek assistance.



- You no longer have any time or place to be alone for even a brief respite.
- Family relationships are breaking down because of the caregiving pressures.
- No matter what you do, it isn’t enough.
- Your relative’s condition is worsening “despite my best efforts.”
- It feels like you are the only person in the world enduring this.
- Your caregiving duties are interfering with your work and social life to an unacceptable degree.
- You realize you’re all alone—doing it all—because you’ve shut out everyone who has offered help.
- You’re coping methods have become destructive: overeating/undereating, abusing drugs/alcohol, or taking it out on your relative.
- There are no more happy times. Loving and caring have given way to exhaustion and resentment and you no longer feel good about yourself or take pride in what you are doing.

If a couple of these danger signals seem to apply to you, connect with a local support group, caregiver counseling, or other support system. If none of these danger signals apply, be proactive. If you find that things you used to do occasionally are now becoming more and more of your daily routine, seek help as needed to avoid deterioration of your health and well-being.

(from *Modern Maturity*, August-September, 1987)

Checklist for the Caregiver

- I am getting out at least once a week.
- I am getting regular exercise.
- I talk with or visit with three friends or relatives weekly.
- I am getting enough sleep at night.
- I keep annual medical and dental appts.
- I am taking only the medication as prescribed to keep up my health.
- I am learning from, and supported by, others involved with caregiving (reading, support groups, 1-1 discussions, etc.).
- My legal and financial papers are in order.
- I allow myself daily pleasures.
- I invite friends to my home for socialization.
- I don’t expect perfection of myself and I take the time to pat myself on the back.
- It’s OK if I feel angry sometimes.
- I take advantage of services for the elderly for my loved one.
- I encourage and accept help from family and friends.

Handling Family Criticism Effectively

Visits from family and friends can be a joyful time for you and your loved one. But it can also bring frustration, hurt feelings and arguments when visitors try to second-guess your caregiving methods and choices. It may seem like they're trying to make your caregiving more difficult than it already is.

When a visitor makes a caregiving suggestion or questions why you're taking care of your loved one in a certain way, be ready to turn the criticism into a positive opportunity for you both.

Your first impulse may be to tell them to mind their own business. But this may alienate the very people who, at other times, have provided (or may provide in the future) support and understanding, according to Carol Simpson, author of *At the Heart of Alzheimer's*. If they love the patient too, caregiving is their business. Their questions may be valid ones. "They deserve to understand why you made the choices you do or why you provide care the way you do."

It may help to examine why they seem so critical. Perhaps you have protected them from the more difficult aspects of caregiving? Do they fully understand the enormous demands on your time? Do they realize the physical challenges you face in providing care? Have they seen your loved one on a "bad" day? Can they appreciate the isolation of full-time caregiving and grief you feel about your feelings and experiences with them? They care about you and don't want to see you become burnt-out or ill.

Criticism, Simpson says, can also come from a family member's or friend's guilt about helping with the caregiving. Offer them opportunities to become part of the caregiving "team." Could they visit more often and provide you a respite--a chance to have some free time, run errands, visit with friends, attend religious events or just rest?

Don't let them just say, "Yes, I'll help." Offer specific tasks or regular times when they can provide a respite. Other ways they could help include providing transportation, cooking a meal or paying for adult day program services. Perhaps they could make some phone calls to locate community services such as personal in-home care, homemaker services, home--delivered meals, health care, case management. Finding a good case worker that will explain eligibility criteria, the application process and provide oversight of the actual services, can make a great deal of difference.

Perhaps you are overreacting to family and friends' questions or suggestions because you're exhausted, depressed or feel like caregiving is your responsibility as your loved one's spouse or child? Their suggestions may be helpful but you're too tired to see a better way of handling caregiving duties. Would a regular break help you better cope with the stress of caregiving?

Does asking for help make you feel like you're taking an irreversible step toward dependency? Does admitting to others that you need help feel like you're giving up on the hope that your loved one will get better? Find a local support group made up of other caregivers. These groups often provide intensely helpful people who understand what you face each day and who can provide realistic suggestions.



Perhaps a frank discussion with your minister or counselor could provide some perspective for your family responsibilities. An honest discussion with the patient's doctor will provide perspective on the expected course of the illness.

Simpson advises that if you've done your best to address the concerns of your family and friends and they still disagree with your decision, remember, as a loving caregiver, you know best what your loved one needs. Sometimes, just a

"thick skin" is all that's needed to handle criticism effectively.

(Excerpted from an article in the December, 2002 issue of Aging Arkansas.)

Dementia Care: Handling Troubling Behavior

Some of the greatest challenges of caring for a loved one with dementia are the personality and behavior changes that often occur. You can best meet these challenges by using creativity, flexibility, patience and compassion. It also helps to not take things personally and maintain your sense of humor. To start, consider these ground rules:



We cannot change the person. The person you are caring for has a brain disorder that shapes who he has become. When you try to control or change his behavior, you'll most likely be unsuccessful or be met with resistance. It's important to:

Try to accommodate the behavior, not control the behavior. For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.

Remember that we can change our behavior or the physical environment. Changing our own behavior will often result in a change in our loved one's behavior.

Check with the doctor first. Behavioral problems may have an underlying medical reason: perhaps the person is in pain or experiencing an adverse side effect from medications. In some cases, like incontinence or hallucinations, there may be some medication or treatment that can assist in managing the problem.

Behavior has a purpose. People with dementia typically cannot tell us what they want or need.

They might do something, like take all the clothes out of the closet on a daily basis, and we wonder why. It is very likely that the person is

fulfilling a need to be busy and productive. Always consider what need the person might be trying to meet with their behavior—and, when possible, try to accommodate them.

Behavior is triggered. It is important to understand that all behavior is triggered—it doesn't occur out of the blue. It might be something a person did or said that triggered a behavior or it could be a change in the physical environment. The root to changing behavior is disrupting the patterns that we create. Try a different approach, or try a different consequence.

What works today, may not tomorrow. The multiple factors that influence troubling behaviors and the natural progression of the disease process means that solutions that are effective today may need to be modified tomorrow—or may no longer work at all. The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

(From the Caregiver's Guide to Understanding Dementia Behaviors. Used with permission of the Family Caregiver Alliance, National Center on Caregiving, For more information, visit www.caregiver.org or call 800-445-8106.)

Middle Stage Dementia Caregiving Series

“Living with Alzheimer’s for the Middle Stage Caregiver,” a three-part series, will be offered by Jessica Cornell of the Alzheimer’s Association of CNY from 10 am to 12 noon on Fridays, July 13, 20, and 27th at Brookdale’s Sterling House (103 Bundy Rd. Ithaca)



The same program will be offered at Lifelong (119 W. Court St., Ithaca) on Tuesdays, September 18, 25, & October 2 from 1:00-3:00 pm.

The program will cover the following topics:

Part One:

- Symptoms of Middle Stage
- Communication
- Relationship Changes
- Providing Personal Care
- Preparing for Hospitalizations

Part Two:

- Behavior Changes
- Medication Management
- Home Safety
- Driving
- Living Alone
- Wandering

Part Three:

- Day Services
- In-Home Care Services
- Senior Living Options
- Caregiver Needs

Reservations are required. Call the Alzheimer’s Association (Rhonda) at 330-1647 x125.

When Nursing Home Care May Be Necessary

The decision to use a nursing home may be necessary due to:

Not enough family members or others available to provide care as needed.

Physical stress—family members cannot handle the physical aspects of care such as lifting patients.

Medical needs—family cannot handle medical aspects of care such as administering oxygen, administering injections, or patient needs other extensive medical care.

Cost of home care—family and/or elderly person cannot afford the cost of all the services needed and public programs cannot meet the need in the home.

Behavior problems compromise the safety or health of the patient or caregiver: wandering, disturbing sleep patterns, aggressive or self-destructive behavior, failure to take medications properly and no way to monitor, inability to control elimination.



To discuss the level of care needed by a loved one, contacts our local NY Connects office (Long Term Care Services) at 274-5222. This office also conducts the Patient Review Instrument (PRI) assessment that is required before nursing home placement. The Office for the Aging can also provide you with checklists to use as a guide to choosing a nursing home. There are also two government-sponsored sites you can refer to when seeking to compare nursing homes:

Medicare’s “Nursing Home Compare”:
www.medicare.gov/NHcompare

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 “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

Next Step in Care: www.nextstepincare.org

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