



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 2015

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Register for Upcoming Programs Sponsored by the Caregivers' Resource Center

Starting later in March, we will again be offering our *Powerful Tools for Caregivers* classes. See page 4 for more information. Please call to register ASAP if you are interested as space is limited. Also, please mark you calendars for these upcoming workshops for family caregivers, which are described in more detail on p. 5. Because of limited space, we do need you to call ahead to pre-register.

All of the following workshops will be held in the Tompkins County Office for the Aging Conference Room 214 W. Martin Luther King, Jr/State Street

February 5, 6:30-8:00 PM: ***Legal and Financial Issues for LGBT Caregivers***
Speaker: Mariette Geldenhuys, Esq.

March 5, 6:30-8:00 PM: ***Creative Self-care for Caregivers***
Speaker: Emily Millen, LCAT

April 9, 6:00 – 7:30 PM ***Transition to Assisted Living or Nursing Home: Is it Time?***
Speaker: Maria Motsavage, RN



Please note that the Alzheimer's Support Group continues to meet at the Office for the Aging on the 4th Tuesday of every month from 1:00-2:30 PM and is open to anyone caring for a loved one with any type of memory impairment/dementia. Information about other workshops and support groups of interest to family caregivers is also contained in this newsletter.

Local Caregiver Support Services

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

Caregivers' Resource Center & Project CARE Services

Tompkins County Office for the Aging

David Stoyell (274-5492)

Katrina Schickel (274-5491)

The Caregivers' Resource Center & Alzheimer's Support Unit

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



Volunteers from **Project CARE** offer caregivers a needed break and help out in other ways as needed. We may also be able to arrange for paid home care services or short-term respite for stressed caregivers having difficulty paying for those services. Call Katrina to discuss your needs.

Caregiver Counseling

Family and Children's Service

Ann Dolan (273-7494)



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

Adult Day Program

Longview Adult Day Community

Monday thru Friday, 9 AM- 3 PM

Pamela Nardi (375-6323)



Adult day programs offer older adults companionship along with planned social and recreational activities. It often provides a break from caregiving and time for other matters. Fee:

Support Groups



Caregiver Support Group

3rd Tuesday of each month

6:30 PM-8:00 PM

Family and Children's Service

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

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

Alzheimer's Support Group

4th Tuesday of each month

1:00-2:30 PM

Tompkins County Office for the Aging

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

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

Other Alzheimer's Caregiver Groups

3rd Wednesday of each month at 5:30 PM

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

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

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

at Walden Place, Cortlandville. Call 756-8101.

Companion care for your loved one available during the meeting.

Dealing with Caregiver Guilt

Caregivers often carry around undeserved guilt, believing they aren't doing enough for their loved ones. This guilt can make the caregiving role even more stressful than it already is. One might ask why a caregiver feels guilty when they're doing such a courageous job. Here are some reasons:

- **Resentment for personal time lost**—It's normal to feel like you're missing something when so much of your time is taken up caring for someone else. The caregiver may think they shouldn't feel this way.
- **Unresolved issues**—Many times, there are issues stemming from childhood or arguments in the past that hinder the caregiving process. Many caregivers shouldn't feel guilty about this.
- **Comparing yourself to others**—Some caregivers will look at another caregiver and think that they could never accomplish what the other person did.
- **Knowing placement is inevitable**—There can be tremendous guilt involved when a caregiver has to place their loved one in assisted living or a nursing home.
- **Dealing with your own issues**—You may be dealing with personal or health problems yourself, which takes away from your caregiving responsibilities.



Ways to Cope with Caregiver Guilt

- **Acknowledge the guilt**—It's normal to feel guilt from time to time. Once it's recognized we are better able to deal with it.
- **Look at the bigger picture**—Although you may be stressed with a particular situation now, it will not last forever. Look at the sacrifices you make for your loved one and realize that you are doing a great job.

- **Accept that you're human and have flaws**-- All of us make mistakes from time to time. Some of us may be good at the physical aspects of caregiving, while others are better at handling the emotional toll. Recognize your strengths. Don't focus on the negative.
- **Make time for yourself**—This is easier said than done, but it's a must! Even if it's just an hour or two a week, go out and have coffee with a friend, catch a movie, attend a caregiver support group, or just curl up and read a book. Taking time out helps you put your situation in better perspective.
- **Know that you are making the best decision for you and your loved one at that time**—This can be hard to accept, especially if you've made a promise in the past that you can no longer keep. A change in a situation may force you to break that promise. Realize that the promise was made under different circumstances. You are making the best decision with new circumstances.
- **Deal with unresolved issues or accept them for what they are**—Many times, we may be taking care of someone who we resent, for many reasons. You can choose to try and resolve those feelings from the past to allow you to care for that person fairly. You can also choose to allow someone else to care for that person because you know you cannot rightfully do so. Either way, this is something you need to consider if your past with that person is an issue for you. Talk to a professional if necessary to make the best decision for both you and your loved one.

Reach out for support from your family and friends; seek caregiver support groups or professional help to work through your feelings of guilt. Know that you are not alone in your caregiving journey and that help is available. Remember you are doing the best that you can!

*By Malika Brown, MSW, LSW. Reproduced with permission from **Today's Caregiver** magazine Copyright 1995-2014. Sign up for their free weekly newsletter at <http://www.caregiver.com>.*

Feeling Stretched?

Let's Face It...

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



Balance Your Life

Powerful
Tools
for **Caregivers**

Spring 2015

Powerful Tools for Caregivers Classes

Powerful Tools for Caregivers is a six-week educational program designed to provide you with the tools you need to take care of *yourself*.

You will learn to:

- Reduce stress
- Improve self-confidence
- Better communicate your feelings
- Balance your life
- Increase your ability to make tough decisions
- Locate helpful resources

The program consists of six - 90 minutes class sessions held weekly and is offered free of charge to caregivers.

Not intended for professional caregivers

March 30 — May 4th (Mondays)

5:00PM—6:30 PM

at the Office for the Aging

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

Pre-registration is Required

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

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

Upcoming Caregivers' Resource Center Workshops

The following workshops are offered free of charge in the conference room of the Tompkins County Office for the Aging, 214 W. Martin Luther King, Jr./State Street, Ithaca.

Preregistration is required as space is limited.

Call the Office for the Aging to register or for details (274-5492).

Legal and Financial Issues for LGBT Caregivers

Thursday, February 5, 2015, 6:30 PM-8:00 PM

Presented by: Mariette Geldenhuys, Esq.



For lesbian, gay, bisexual and transgender (LGBT) people, certain legal and financial decisions become increasingly important as they age. These determine who has the responsibility to provide care, the power to make medical decisions, and the legal authority to utilize financial resources on someone's behalf if he or she is incapacitated. Also, whether or not same-sex partners are married may have a financial impact on responsibilities to support a partner as well as affect eligibility for Medicaid coverage of long-term care expenses.

In this workshop Ms. Geldenhuys, a local attorney, will discuss these and other issues of concern to LGBT caregiving partners or those wanting to plan ahead for the likelihood of future caregiving by an LGBT spouse, partner or friend.

Creative Self-Care for Caregivers

Thursday, March 5, 6:30-8:00 PM

Presented by: Emily Millen, MS, LCAT



In this workshop, Ms. Millen, a certified Art Therapist, will first provide you with information to add to your collection of self-care practices which are most soothing to the nervous system. She will then move from a short mindfulness practice into an image-making experience. Art-making allows us to move into a state of flow, which is a deeply creative, rejuvenating state. You will be guided into connecting with an instinctive aspect of yourself, allowing for respite from thinking, planning and multitasking. You will leave the workshop with a meaningful personal healing image and a process you can then use as needed to access this intuitive, restful place.

I Promised Mom I Would Always Take Care of Her

Thursday, April 9, 6:00-7:30 PM

Presented by: Maria Motsavage, RN, LNHA



When is it time to consider a transition to Assisted Living or a Nursing Home? Maria Motsavage, RN, LNHA, will discuss elements of caregiving burden and the concerns and decisions caregivers face when a loved one is no longer able to be cared for safely at home. She will discuss the role of the caregiver after a transition to another level of care. Ms. Motsavage is currently the Elder Care Coordinator for the law firm of Levene, Gouldin and Thompson, LLP and a former nursing home administrator.

News and Notes

Longview's Day Program Expands

Beginning January 12th, Longview expanded its Social Adult Day Program to five days a week. The program serves individuals age 55+ who may be alone during the day, as well as providing a respite for their caregivers. It provides a stimulating social and recreational environment outside of the home, assuring families that their loved ones are well cared for and immersed in an active lifestyle with peers. Participants enjoy a variety of programs, socialize with residents & guests, and have lunch in the dining room overlooking Cayuga Lake. Day Program participants can also make use of the beauty salon and on-site massage therapy services.



Participants are free to choose a schedule that fits their needs. Some choose to attend all five days, others one or two, and some even participate for half days. All program participants enjoy lunch with the Adult Day staff in the Longview dining room. Fee: \$45/fullday, \$31/half day with lunch, \$22 half day without lunch. For more information about Longview's Social Adult Day Program, call the Program Coordinators at (607) 375-6323 or email pnardi@ithaca.edu or mwhittaker@ithaca.edu.

"The Human Hand in How We Die"

Holly Prigerson, PhD, will give the distinguished speaker address in Emerson Suites, Phillips Hall at Ithaca College on Monday, February 16 at 7:00 PM. Ms. Prigerson, the Director of the Center for Research on End of Life Care at Weill Cornell Medical College will speak on the topic: *On Being Mortal: The Human Hand in How We*



Die. She will discuss research findings from the Coping with Cancer Study, a National Institute of Health funded study involving patients and caregivers in 8 outpatient cancer clinics across the United States. Her talk will highlight the factors affecting end-of-life decision making and provide suggestions on how to improve the quality of care. The event is free and open to the public. For information, contact Teri Reinemann, 607-274-1607, or email treinemann@ithaca.edu.

A Sibling's Guide

Bonnie Lawrence, Senior Editor for the Family Caregiver Alliance, based in San Francisco, has written an information article titled *A Sibling's Guide to Caring for Aging Parents*. Siblings often disagree on the best approach to caring aging parents. This article talks about how to identify the family dynamics that can impact shared caregiving, ways your siblings can help, how to increase the chances of getting that help, and how to deal with emotions that arise. You can read it online at <http://www.pbs.org/newshour/updates/youre-sharing-care-aging-parents/>.



The Family Caregiver Alliance also has articles of interest to family caregivers on topics such as:

Hiring In-Home Help

Background Checking: Resources that Help

Talking with Your Parents about Disability

When Caregiving Ends

View them online at www.caregiver.org. (Type the name of the article or other topic into the "Search" window.) If you do not have Internet access, call the Office for the Aging (David Stoyell, 274-5492) and ask to be mailed a copy of any of the articles referenced in this newsletter that you want to read.

Addressing the Needs of the Invisible Patient

Very few caregivers are ever asked by their loved one's doctors or other professionals how they are coping with the care of another. Questions like whether the caregiver is eating properly, exercising, sleeping enough, become depressed, or getting any free time are often overlooked. Thankfully, some physicians and other healthcare professionals have noticed the lack of care given to the actual caregivers, and are doing something about it.

Dr. Ronald D. Adelman, co-chief of geriatrics and palliative medicine at Weill Cornell Medical College recently gave a talk in addition to publishing an article about "the invisible patient," the caregivers of the elderly. He contends that doctors should be assessing caregivers when they check on their elderly patients.

The invisible patient refers specifically to a person supporting an elderly family member with dementia, heart disease, diabetes, or all of the above. Currently in the United States there are over 43.5 million people providing this type of care to a loved one over the age of fifty.

Recommendations for Caregiver Assessment

Dr. Adelman also recently published an article in the Journal of the American Medical Association discussing the burden of caregivers with the objectives of providing strategies to diagnose, assess, and intervene for caregiver burden in clinical practice as well as evaluating evidence on interventions intended to avert or mitigate caregiver burden and related caregiver distress. He found that physicians have a responsibility to recognize caregiver burden. In addition, caregiver assessment and intervention should be tailored to the individual circumstances and contexts in which caregiver burden occurs.

In his view, some of the risk factors for the invisible patient that should trigger assessment by doctors include:

1. Being a woman
2. The number of hours of care provided
3. The complexity of medical tasks such as dealing with wounds, catheters and complex medication routines
4. Transitions from one kind and location of care to another, like from home to hospital, to rehab, to skilled nursing care or to hospice
5. Financial distress
6. Level of cognitive impairment in the patient
7. A less educated caregiver
8. A caregiver who lives with the patient
9. A lack of choice in assuming the caregiving role

The recommendations given in the article for treating physicians are fairly straightforward. It includes asking a caregiver a simple question like how they are doing, to more complex questions about making other arrangements for care if something were to happen to the caregiver.



Whether or not your loved one's physician asks questions to determine how you are handling caregiver burden, you need to be alert to the presence of risk factors in your life and take inventory of how you are doing with your own self care.

Two tools you can use in doing a caregiver self-assessment are the "Nebraska Caregiver Self-Assessment" found online at

<https://nrrs.ne.gov/caregivermatch/caregiver.php>

It will help you get in touch with any problems you are having.

A second "Self-care Inventory" can be found at http://www.nami.org/Content/NavigationMenu/Intranet/Homefront/Self-Care_Inventory.pdf.

It will help you identify self-care tools to help meet your physical, emotional, social, and spiritual needs.

Aid and Attendance Benefit

Some veterans who need long-term care services like in-home care, or residence in assisting living or a nursing home can receive financial assistance through the VA pension benefit called “Aid and Attendance” This often-overlooked benefit provides money to veterans/surviving spouses who need help with day-to-day tasks (activities of daily living like dressing, eating, bathing, toileting).

Aid and Attendance is available to those who served for at least 90 days, with at least one of those days occurring during wartime, and to their surviving spouse. (Individuals who are blind or in a nursing home also qualify for a benefit.) The disabilities do not need to be service-related.



To qualify, the veteran or surviving spouse must own less than \$80,000 in assets, with home and vehicle not included in this calculation. His or her income must also be lower than the Maximum Annual Pension Rate (MAPR) (\$21,466 for single veteran, \$25,448 for veteran with spouse/dependent, \$13,794 for surviving spouse) after adjusting for unreimbursed costs of aid service, residential care and other medical expenses.

So veterans who have an income that has been too high to qualify for a VA Pension may qualify for this benefit, as long as they have high medical and long term care costs that are not otherwise reimbursed.

The VA pays the difference between the veteran’s adjusted income and the MAPR.

Palliative Care and Hospice Care

What is palliative care? Palliative care gives patients and caregivers extra support during a serious illness. The patient continues to get treatments to help cure the illness. A team of specialists helps relieve pain and symptoms such as fatigue, anxiety, nausea, and depression. The team helps patients and families work through difficult medical decisions. Palliative care is most helpful when it is started early. For example, people with advanced cancer who get palliative care early report better control of pain and other symptoms. And they have lower depression rates than those not getting palliative care. Research suggests that palliative care may even help patients live longer.

What is hospice care? Hospice care is a type of palliative care. Hospice begins when patients and their families decide they don’t want to continue treatment to try to cure their disease. People may start hospice because their treatment is not helping or is too painful. Hospice care tries to keep the patient as comfortable as possible.

When to discuss palliative or hospice care. If you are taking care of someone with a serious illness, it’s never too soon to discuss palliative or hospice care. Remember that this doesn’t mean that you are “giving up.” It means that you are trying to keep your loved one as comfortable as possible.

From the American Academy of Hospice and Palliative Medicine and Palliative Care Organization

Hospicare provides hospice care and palliative care services to residents of Tompkins and Cortland Counties. Call 607-272-0212 to learn more about their services or discuss your loved one’s situation.



Alzheimer's Notes

New Monthly Email Bulletin

We have started sending a monthly email bulletin to those caring for loved ones who have Alzheimer's or other disorder that causes dementia. It includes reminders of upcoming programs of the Caregivers' Resource Center at the Office for the Aging, and an article of interest to family caregivers of persons with Alzheimer's or related disorders. If you would like to be added to this email distribution list, please email dstoyell@tompkins-co.org indicating that you would like to start receiving the "Dementia Caregivers' Monthly Bulletin."



Early Stage Alzheimer's Group

This is a group for those who have a diagnosis of early stage Alzheimer's disease, or those who have symptoms but have not been diagnosed meets on the 3rd Wednesday of every month from 3:30-4:30 PM at Longview, 1 Bella Vista Dr., Ithaca. Call for a pre-screen phone interview. For more information, contact Kim Owen at 375-6320 or kowen@ithaca.edu.



Legal and Financial Planning for Dementia Caregivers

Thursday, January 29, 5pm – 7pm
at the Tompkins County Public Library

If you or someone you know is affected by Alzheimer's disease or dementia, planning for the future is important. This two-part series will give an overview of pertinent legal documents such as wills, powers of attorney, and health care proxies, as well as an overview of financial issues and options like Medicare, Medicaid or veterans benefits. It is strongly recommended that you attend both sessions. Reservations required. To register or for more information, contact Katrina Skeval at the Alzheimer's Association, 315-472-4201 ext.103, or kskeval@alz.org.

Traveling Overnight

Taking a person with Alzheimer's on an overnight trip is a challenge. Some tips from the National Institution on Aging's Alzheimer's Disease Education and Referral Center:

Plan Ahead

- Talk with the person's doctor about medicines to calm someone who gets upset when traveling
- Find someone to help you at the airport, train station or bus station
- Pack items the person enjoys looking at or holding for comfort.
- Include doctors' names and contact info along with a copy of the person's medical record.
- Take a extra set of clothing (in a carry-on bag)
- Perhaps travel with another family member or friend
- Make sure the person wears an ID bracelet or something that tells others who he or she is.
- Carry a recent photo of the person with you.



After You Arrive

- Allow lots of time for each thing you want to do. Don't plan too much.
- Plan rest periods.
- Follow a routine like the one you use at home (e.g., eating, resting and going to bed at the same time he/she does at home.)
- Leave the bathroom light on at night.
- Be prepared to cut your visit short, if necessary.

Remind people you visit:

- To be calm and not use a loud voice or talk to the person with dementia as if a child.
- Make eye contact & call the person by name.
- Remind the person who you are.
- Don't argue if the person is confused. Respond to the feelings they express.
- Have some kind of activity, such as a familiar photo album to look at when bored. Be prepared to skip it if it is not needed.

The Caregivers' Resource Center and Alzheimer's Support Unit

Please call or visit us
at the Tompkins County Office for the Aging
214 W. Martin Luther King, Jr./State Street, Ithaca.
(Open weekdays, 8:30 AM - 4:30 PM)

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Websites of Interest to Family Caregivers:

Tompkins County Office for the Aging: www.tompkinscountyny.gov/cofa

**Click on "Local Resources for Older Adults" to access our Tompkins County resource guides.*

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

Family Caregiver Alliance: www.caregiver.org

Caregiver Action Network: www.caregiveraction.org

AARP Caregiver Resource Center: www.aarp.org/home-family/caregiving

Next Step in Care: www.nextstepincare.org

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