



Spring 2020 Vol. 37

In Support of Caregivers

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

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Local Caregiver Support Services

Caregiver's Resource Center & Project Care Services

Tompkins County Office for the Aging

Rodney Maine 274-5491

Dawn Sprague 274-5499

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

Volunteers with *Project CARE* offer caregivers a needed break and help 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 Dawn to discuss your needs.

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Caregiver Counseling

Family and Children's Services
Ann Dolan 273-7494

A caregiver counselor will meet with family caregivers periodically in her office to help them work through complex caregiving issues or provide emotional support. Special circumstances may be considered for in-home service. No charge. Donations accepted.

Adult Day Program

Longview Adult Day Community
Monday through Friday, 9am-3pm
Pamela Nardi 375-6323

Adult day programs offer older adults companionship along with planned social and recreational activities. It often provides a break from caregiving and time for other matters. Fee: \$55/day includes lunch and snack.





Caregiver Support Group at Brookdale

Last Thursday of every month at 5:30pm at Brookdale, 103 Bundy Rd. Ithaca. Light meal provided. Facilitated by Bruce Rogers. For more information contact Lisa: 342-6050.

Family Caregiver Support Group

1st Tuesday of the Month at 11 at the Tompkins County Office for the Aging, 214 W. Martin Luther King Jr. / State St., Ithaca. To register or for more information call 274-5491.

Alzheimer's Caregiver Groups

1st Wednesday of the month at 5:30pm at Lifelong, 119 W. Court St., Ithaca. For information call the Alzheimer's Association at 330-1647

3rd Wednesday of the month at 12:30 at Walden Place, Cortlandville. Call 756-8101. Companion care for your loved one available during the meeting.67910

Cancer Caregiver Group

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

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

Parkinson's Caregivers Group

1st Monday of each month,11:00am-12:30pm at The *Office for the Aging*. Call the Office for the Aging. 274-5491 for more information.

Funding for Family Caregiver Respite

The Tompkins County Office for the Aging has a limited amount of funding to help family caregivers afford to hire substitute care that enables them to take a break from caregiving, usually a few hours a week. We have some uncommitted funds available if you know a family caregiver who might want to take advantage of this opportunity.

Eligibility:

Title IIIE Respite: This is federal funding that pays for respite service for family caregivers who are caring for an older adult (60 or older) who needs assistance with 2 or more ADL's (dressing, bathing, incontinence, transferring, toileting, eating) **OR** needs substantial supervision due to cognitive impairment (e.g., Alzheimer's or other dementia).

Alzheimer's Respite Scholarships: This is New York State funding granted to Tompkins County through the CNY Alzheimer's Association. This funding pays for respite service (at home or in a licensed care facility) to give a break to family caregivers of persons diagnosed with Alzheimer's or other dementia.

Although neither program is means-tested, we do try to target these funds to those who find it difficult to privately hire enough substitute care.

To Apply or Inquire:

Please encourage family caregivers to contact **Joanne Wilcox** or **Terry McCann** at **Tompkins County Adult and Long Term Care Services (607-274-5278).** Due to the overall shortage of aides, or if clients prefer it, they may able to use this funding to privately hire friends or relatives or aides listed with the Finger Lakes Independence Center (FLIC) through FLIC's Consumer Directed Personal Assistance Program (CDPAP)."

When Neighbors and Friends Become the Caregivers

Steps long-distance caregivers can take to embrace these informal social networks

by Barry J. Jacobs, AARP, June 4, 2019

Fred's argument with his 85-year-old mother, Sarah, about her safety and security was always the same — and he always lost. He lived two states away and wanted her to move from her three-story home of 50 years to a one-floor senior apartment near him where she'd be less likely to get hurt from a fall. In their weekly calls, he insisted she needed to accept this inevitable change.

But Sarah stoutly resisted, arguing that her close-at-hand neighbors were providing her with all she needed to stay in the home she loved. The young family next door frequently paid her visits and brought her a dinner plate. The volunteers at the fire department down the block helped with repairs in return for Sarah's pound cake. Her church group stopped by every Sunday afternoon for gossip and tea.

At a time when many families are dispersed around the country and family gettogethers occur more often on FaceTime than at kitchen tables, it's neighbors who sometimes step up to help an aging parent day-to-day. They pick up groceries and medications on a regular basis. They shovel snow and cut grass without even having to be asked. They check on older adults during heat waves, cold snaps and bad storms. Their commitment isn't as deep or long-standing as that based on blood relation. But their kindness can make them integral members of informal caregiving teams.

It's the informality of the arrangement that sometimes concerns long-distance caregivers, however. Are the neighbors trustworthy and reliable? Will they really be there and know what to do in the event of an emergency? It's one thing to pick up a gallon of milk or even lift someone who's fallen; it's another to sit in the ER for four hours. And what if they move away long before then? Or get caught up in their own problems and then become unavailable?

But family caregiving has never been strictly a family matter. We live in social environments surrounded by social supports. If family caregivers like Fred devote time to engaging their aging parents' most natural social networks — friends and neighbors — then they may be able to coordinate efforts with them. Care receivers like Sarah are not likely to balk at that. How can family caregivers achieve this goal?

Here are some ideas:

Meet the "starting five."

You may already know which acquaintances your parent turns to for help, or you can directly ask by using a basketball analogy to inquire about her "starting five" — that is, the five people upon whom she normally most relies. You and other family members may be on that all-star list, but so may an across-the-street neighbor, the middle-schooler who walks her dog, a dear friend or the funny Meals on Wheels deliveryman. As with any basketball team, all of you may have distinct roles. But unlike in basketball, the members may scarcely be aware of each other's existence as the top players of Team Sarah.

Make a point of meeting individually with the starting five the next time you visit your parent. Offer your thanks for all they've done and make sure they are comfortable continuing to play this role. Explain that they are valued members of a team that helps your parent to live as well as possible but that the team needs a strategy and plays. Get their permission for you to regularly confer with them about how your parent seems to be coping. Then shower them with gratitude and maybe the occasional formal thank-you note. The team will be better coordinated and effective over time, especially important if the parent's level of functioning declines

Seek community exchange forums.

More American communities and religious congregations are setting up time banks or other forums in which neighbors can barter services with other neighbors. For example, you may clear branches from my mom's front lawn today; I then agree to drive your mom to her medical appointment tomorrow. This straightforward trade (with no money involved) of simple essentials can be the difference between an older adult aging in place or departing. It also encourages those who are reluctant to take handouts to participate in a give-and-take. Call the local Area Agency on Aging (which you can find using the federal government's Eldercare Locator) to find out whether your parent's community has such an exchange forum.

Don't dwell on the thickness of blood.

Never resent the involvement of the family next door. It is rarely a replacement for the real family but can be helpful eyes, ears and arms on the ground. It extends your reach and helps your loved one live fully as she wants.

<u>Barry J. Jacobs</u>, a clinical psychologist, family therapist and healthcare consultant, is the co-author of the book <u>AARP Meditations for Caregivers</u> (Da Capo, 2016). Follow him on <u>Twitter</u> and <u>Facebook</u>.

NYS Long-Term Care Ombudsman Program (LTCOP)

Serving Tompkins, Chemung, and Schuyler Counties

Educate Empower Advocate

Certified Long-Term Care Ombudsmen provide free-of-charge services to individuals who reside in long term care facilities (nursing homes, assisted living and adult-care facilities) and the relatives and friends who act on their behalf.

A trained and certified Long-Term Care Ombudsman conducts regular facility visits, helps identify and resolve concerns, and acts as an advocate for residents on issues regarding:

- · Quality of care
- Abuse and neglect
- Rights violations
- Lost and stolen belongings
- Dietary concerns
- Discharge, eviction or termination of services
- Public benefits programs
- Cost of care

For more information or to volunteer:

www.ltcombudsman.ny.gov or 607-274-5498





Volunteer Spotlight: Q&A with Steve

With so many great organizations to support, why should others choose to support LTCOP?

LTCOP provides a vital advocacy service for those who are unable to speak and act for themselves. The program helps residents by investigating and working to resolve resident complaints.

What was most surprising to you about the LTCOP Program?

The program provides an excellent inservice training program in areas of elder law, Medicare and Medicaid provisions, communications strategies for reaching memory impaired residents and elder abuse

Why do you continue to support LTCOP?

So many residents I meet have no families nearby or friends or members of a faith community that help them resolve small and bigger problems.

How has this program changed you?

It has made me more knowledgeable on issues facing our nation's growing senior citizen population and how these issues can be resolved.

New to The Caregiver Library at the Tompkins County Office for the Aging:

"Passages in Caregiving" by Gail Sheehy

"Everything You Need to Know About Caregiving for Parkinson's Disease" by Lianna Marie

"Getting Real About Getting Older" by Linda K. Stroh and Karen K. Brees

"Inside the Dementia Epidemic" by Martha Stettinius

"Creating Moments of Joy Along the Caregiving Journey" by Jolene Brackey

"The Grandfamily Guidebook" by Andrew Adesman and Christine Adamec

"The Unexpected Journey of Caring" by Donna Thomson and Zachary White

"The Caregiver's Toolbox" by Carolyn P. Hartley and Peter Wong

"The Emotional Survival Guide for Caregivers" by Barry Jacobs

We have many books available for you to borrow from our Caregiver Library. Stop in and see what we have!

Personal Emergency Response Systems



Are you concerned about the safety of a family member or a friend? Are you, or someone you know, at risk for falling in their home? Tompkins County Office for the Aging can help!

We contract with Doyle Medical Monitoring to provide Personal Emergency Response Systems (PERS) to residents of Tompkins County. Standard pricing starts at \$25 a month and there is no installation, cancellation, or service call fee. When you get a PERS through our office, an Outreach Worker will visit your home, install and test the device, and explain how it works. With our Personal Emergency Response Systems, you will receive personalized in-home service, peace of mind, services and connections from a local agency, and 24/7 monitoring service. Call the Office for the Aging today at 607-274-5482 to speak with an Outreach Worker about our devices!



Family Conflict: Caregiving Can Affect Relationship With Loved One

The care recipient still should make some decisions; some changes can be introduced slowly

by Stacey Colino, AARP, October 30, 2019

Caring for an older loved one can affect the dynamics in the relationship.

"The relationship can start to feel different when one person becomes dependent on the other, or you can start to feel like your parent's parent," says Nancy Schlossberg, professor emerita of counseling psychology at the University of Maryland and author of *Too Young to Be Old*.

Meanwhile, you may feel angry or frustrated that your parent has become ill. Or you may feel guilty because you wish that you didn't have to be the caregiver.

By contrast, your parent may feel resentful about being so dependent or losing the ability to care for himself or herself but also may feel grateful for your help, she says. Here are steps you can take to avoid stirring up unpleasant feelings and keep the relationship on an even keel:

1. Ask loved ones how they want to age

"When the conversation is approached in that framework, it works better because it preserves the parent's dignity," says Barry J. Jacobs, a clinical psychologist, health care consultant and AARP columnist.

"If you can agree on an overarching goal, it's easier to figure out how to get there," he says.

Still, it's important to create contingency plans if things don't go well with a particular living situation or care arrangement.

2. Respect your loved one's wishes

"Let the parent make as many decisions as he or she can," Schlossberg says. Whether that means choosing what to have for lunch, deciding what to watch on TV, or picking a museum or a garden for an outing, letting loved ones have a say in the decision-making preserves their dignity and sense of autonomy. This, in turn, will ease the care recipient's sense of dependency and the caregiver's decision burden. Also, "take steps to guard the loved one's privacy by not hovering too much," says Eve Markowitz Preston, a psychologist in private practice in New York City who serves mostly older adults and often makes home visits.

3. Make adjustments

If your loved one wants to do something that's not realistic because of that person's physical or cognitive limitations, "validate the person's wishes but encourage adjustments to maintain safety," Preston says.

That might mean taking a wheelchair or a scooter to the park rather than letting your loved one walk the whole time. If a parent wants to remain in her home, but it isn't safe for her to cook for herself, you might bring in a home-health aide for a certain number of hours to assist and supervise.

"It all comes down to (this): How do you care for your parent and enable them to live the way they want for as long as possible without taking over their lives," Jacobs says.

4. Introduce changes slowly

In altering a loved one's routines or living situation, "often there's time to plant the seeds for change," Jacobs says.

If major changes are in order, suggest modifications and explain why they're important, whether for convenience, optimal care, safety or another reason.

"Let the issue lie, then come back to it," Jacobs says. "Make changes slowly so people have a chance to adjust to the idea."

5. Present a united front

If your loved one is in denial about the need for certain changes or forms of care or puts up a fight for other reasons, remember that "sometimes there's strength in numbers," Jacobs says.

"If you and your siblings agree (about what's best for Mom or Dad), you can speak with one voice, which can help overcome the parent's resistance," he says.

The idea isn't to gang up on the parent but to gently explain the rationale behind making certain changes. This approach can help divert conflict.

6. Find new sources of positivity

Engage your loved one wherever he or she is.

If the person is functioning well, consider doing an art project, assembling a puzzle or cooking together. If the person is ill, "spend time reminiscing and looking at photo albums together," Schlossberg says.

"Be a good listener," she says. "Don't mind if you've heard the story before." Alternatively, you could listen to an interesting audiobook together. Besides boosting your loved one's mood, sharing positive experiences like these can strengthen the connection between you.

Family Conflict: Primary Caregiver Often Pitted Against Siblings

Simmering rivalries from the past can fuel problems, but frequent communication is key

by Stacey Colino, AARP, October 28, 2019

Old resentments and rivalries often die hard, especially with sibling relationships, and caregiving situations can resurrect these issues.

This is especially true if one adult child is doing the lion's share of the caregiving work, with little support from siblings, or if one person is footing the bill for paid caregiving or medical expenses. In other instances, power struggles can occur between older and younger siblings who think they know what's best for Mom or Dad and want to have control of caregiving decisions.

Complicating matters, "parents often have preferences for which child will be the primary caregiver, which may stir up resentments with siblings," says Barry J. Jacobs, a clinical psychologist, health care consultant and AARP caregiving expert.

"How you behave with one another can affect your sibling relationships for the rest of your lives," he observes. "When you pull together and work together, it can strengthen the relationship. When you don't, it can weaken the relationship."

Here are smart strategies that can help you navigate potential minefields with your siblings:

1. Come up with a consensus

Schedule a meeting with your siblings, either in person or on a conference call, to "discuss your parent's condition, what the caregiving needs are and what's likely to happen going forward," Jacobs says.

Once you are in general agreement, devise a caregiving plan that addresses who will play each role. Someone will do the bulk of the work; others will be supporting players or provide respite care.

At least every quarter, reevaluate what's happening with your loved one and how her needs are changing. Refine the plan as necessary.

2. Establish an appropriate division of labor

Consider which sibling is best suited to which responsibilities, based on abilities, financial resources, proximity to the care recipient, time availability and other key factors.

Be flexible about shifting responsibilities from one sibling to another as each sibling's situation changes, Jacobs says.

3. Figure out how to stay in touch

Agree to keep one another apprised of any changes in your family member's condition or needs.

Decide together on the best or preferred mode of communication (perhaps group texts or email) for sharing important information between scheduled meetings, Jacobs says. Then rely on it as issues crop up or change.

4. Ask for what you need

If you are the primary caregiver, avoid setting yourself up to shoulder every caregiving task or decision, as this can lead to resentment and burnout. Become an assertive, direct communicator and spell out what specific assistance you need — whether it's financial help or a break from watching your older family member.

"If you don't express what you need, you can't expect other family members to read your mind," says Dolores Gallagher-Thompson, a visiting professor at the Betty Irene Moore School of Nursing at the University of California, Davis.

5. Consider outside help

If longstanding sibling tensions and resentments get in the way of your pulling together to provide your loved one with optimal care, seek counseling to help all of you work through issues, Gallagher-Thompson advises.

Remember, the care recipient suffers the most when tasks trigger intractable power struggles and resentments among siblings, Jacobs says. If each of you can remember that and try to work through or put aside grievances for the greater good of helping your family member, you'll be better at getting the job done.

And by working together, you may even improve your sibling relationship.

Stacey Colino is an independent, award-winning writer specializing in health, psychology and family issues. Her work has appeared in dozens of national magazines as well as on websites and in books.

Project CARE



Project CARE is a **friendly visitor program** in Tompkins County for Seniors age 60 and over. Project CARE provides companionship to Seniors by having a volunteer make a weekly visit. Project CARE can be a great comfort to Seniors by providing in-home support and companionship, especially to frail or homebound older adults, those that are socially isolated, as well as family caregivers.

Weekly visiting:

Many Seniors in our community greatly benefit from a weekly visit. Visits provide a caring bond, especially to those who are socially isolated. Volunteers can provide conversation, support, organize calendars/paperwork, play games, go for a walk, read to their Senior, polish nails, do a puzzle together, and much more.

If you are interested in having a Project CARE friendly visitor please contact Dawn Sprague at NY Connects Tompkins County Office for the Aging by phone @ (607)274-5499 or email @ dsprague@tompkins-co.org to discuss this opportunity further.

The Registry at FLIC



The Registry is a compiled list of private pay aides who have been screened through a face to face interview with the Registry Coordinator at FLIC. References are provided and verified to make sure the aide has the necessary skills and compassion that are important for someone to have when taking care of people in their homes. The Registry also contains a list of skilled nurses varying from pediatrics to palliative care.

For more information contact Teri Reinemann at 272-2433.

The Registry program is made possible through funding from the Tompkins County Office for the Aging and the New York State Office for the Aging.

NEWS AND NOTES

Home Energy Assistance Program (HEAP)

This year's HEAP Program is closing April 24th, 2020

The Home Energy Assistance Program (HEAP) provides assistance with fuel and utility expenses for income-eligible homeowners and renters. The HEAP program may also be able to help with furnace repair or replacement. The Tompkins County Office for the Aging processes HEAP applications for persons over age 60, and for those who receive SSI, or SSD, and do not receive Food Stamps.

The current income eligibility levels for HEAP in 2019-2020 are as follows:

Household Size 1	Maximum Gross Monthly Income \$2,494
2	\$3,262
3	\$4,030

If you think you may be eligible for HEAP, contact the Tompkins County Office for the Aging (607) 274-5482 for more information.

Reminder!!! You can always contact the Office for the Aging for information and referral on Caregiver and Long-Term Care services at 274-5482.

If you would like to be taken off our mailing list, or if you would like to be taken off our mailing list but added to our Email list, please contact us!

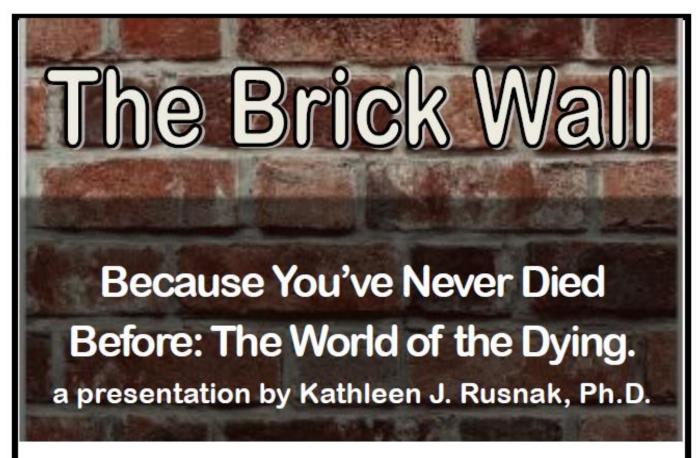
Thank you!!

It is with regret that the Tompkins County Office for the Aging has decided to cancel this year's Senior Living Expo that was scheduled on Saturday, March 28th. This decision was made with guidance from the Tompkins County Health Department and Leadership Team, amid the growing concerns about the COVID-19 virus. Older Adults are considered a vulnerable group, particularly those with pre-existing conditions and have been most negatively affected by this virus. The health and safety of older adults, our staff and the community-based organizations who provide services and supports are our highest priority.

We are unable to reschedule this year and will look forward to next year. Please note our office is always available to provide information and assistance regarding the resources in our community that assist older adults in their daily lives. Please reach out to us at 607-274-5482 if you have any questions or concerns. Also if you want to get more information and/or monitor the latest developments on COVID-19 please see the Tompkins County Health Department's website www.tompkinscountyny.gov/health

Thank you for your understanding and support!





"What makes Kathleen's presentations so appealing—when her subject matter is so naturally unappealing, like death, dying, the Holocaust, or evil—is her talking openly, unabashedly, and humorously about her own thoughts and experiences that we secretly, and sometimes unsettingly, think *only* we think about or *only* we go through. We discover that everyone else in the audience is also seeing themselves in what she saying, and we all laugh aloud, feeling the pungent pull of permission—to be more human to ourselves and others."



Saturday, March 21, 9am-12pm

First Presbyterian Church of Ithaca 315 N Cayuga St, Ithaca, NY 607-272-2800

Free and open to the public.

If bringing a group, please RSVP in advance

Q and A and reception to follow

Co-Sponsored by:







In this time of uncertainty, please check the website prior to the event for possible notice of cancellation.

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

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Dawn Sprague, Project CARE Coordinator and Newsletter

Editor

Telephone: 607-274-5499

Email: dsprague@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 quides.

Family Caregiver Alliance: www.caregiver.org

CaringBridge: www.caringbridge.org

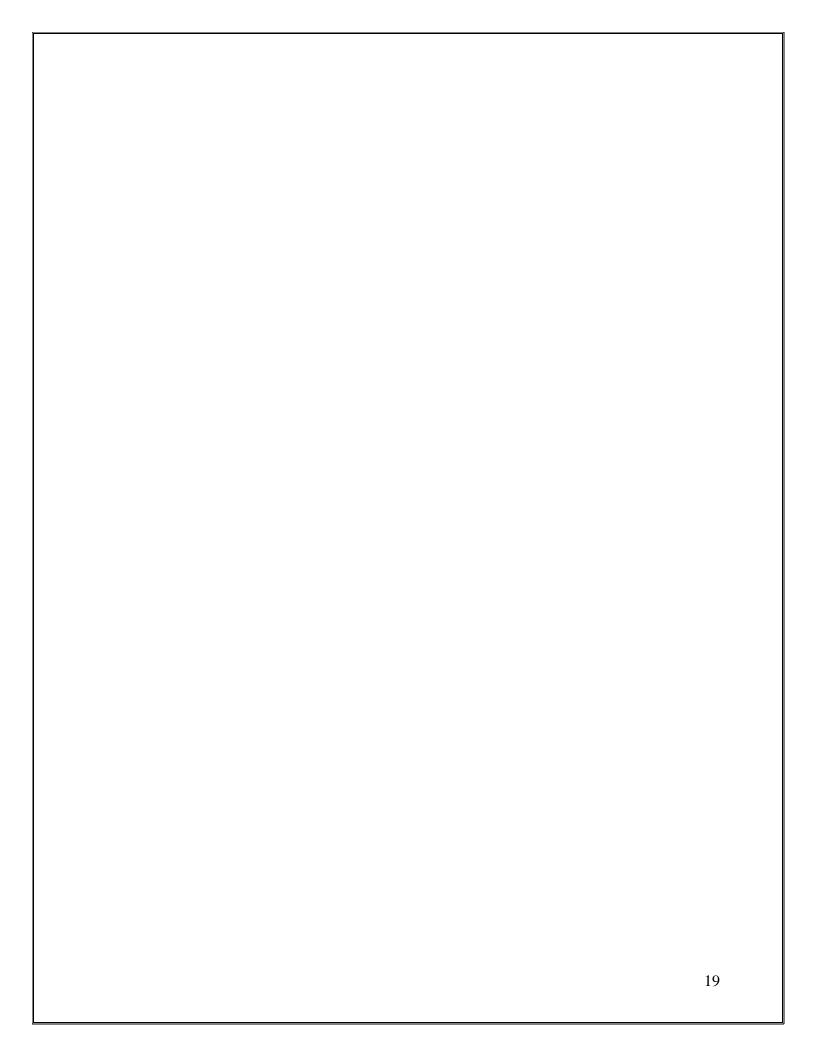
Caregiver Action Network: www.caregiveraction.org

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

Next Step in Care: www.nextstepincare.org

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