

*Serving Elders and Others since 1991*



# CARING FOR THE CAREGIVER



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*Vol 12 • Issue 1*



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Creative Case Management (CCM) is a professional story and a personal story.

Charlotte Bishop started CCM more than 20 years ago. Soon after that Charlotte's husband was diagnosed with brain cancer. Charlotte became her own spouse's personal case manager until his untimely death three years later. This personal journey evolved into a professional journey and certification as a Geriatric Care Manager (GCM) and the part of CCM dedicated to "Serving Elders and Others."

*Creative Case Management* is a team of certificated professionals providing answers to older adults in Illinois and their families.

## CARING FOR THE CAREGIVER

As a Geriatric Care Manager (GCM), I am often involved in helping the caregiver as much as lending assistance and resources to the elder or other person with special needs. Sometimes it is as simple as helping a caregiver to recognize in themselves the signs and symptoms of burnout.

Starting out with first things first: Who should attend to the caregiver? There are external supports that can be as basic as just giving a break to what some have characterized as a 36 hour day that many caregivers live. But the other side of this is to watch for your own symptoms as a caregiver and be as good for yourself as you are for your loved one who depends on you. Do you see the signs? Are you missing a lot of work? Are you not able to pay certain bills? Are you not exercising and instead eating a lot of unhealthy foods? Are you having nightmares or disturbing dreams? Are you feeling lethargic or maybe even depressed? Are you angered by minor issues, or are you impatient with your loved one?

If you can answer any of these questions with a "yes," you need to know that there are resources and support systems that can help. Family, friends, volunteers, and GCMs are all helpful. Getting your own support doesn't mean you are losing a battle, but it means you are getting through it.

### To address your needs as a caregiver, you should:

- ✓ Become educated about your loved one's condition in order to be as effective as you can be.
- ✓ Recognize that you are not superman or superwoman; set some limits on what you and others can expect from you.
- ✓ Do not beat yourself up about feeling angry, afraid or even resentful; instead find ways to vent.
- ✓ Talk is important, especially to a therapist or counselor or clergy member...even trusted friends as a principal way to vent.
- ✓ Lift smart. As a caregiver, be smart about not hurting your back when lifting, pushing and pulling; keep yourself in shape and use an assistive waistband if your physician recommends it.

Finally, appreciate that caregiving is a job, and that all jobs allow one to "punch out" from work as well as take vacations and breaks. Give yourself permission to take a respite from caregiving. Many local hospitals or senior residential facilities have "respite care programs" open to the community at large.

Most states have Agencies on Aging, such as the Illinois Agency on Aging <http://www.state.il.us/aging/>. Also, check on line with the National Family Caregiver's Association <http://www.nfcares.org/>.

## AARP'S REPORT ON CAREGIVING

At the personal level caregiving truly is an enormous responsibility with great demands on a person's time and their emotional well-being. The most recent report on family caregiving published by AARP (<http://assets.aarp.org/rgcenter/ppi/lte/i51-caregiving.pdf>), however, really provides a sense of the huge and important work that caregivers are providing for their families in America today. It is required reading for caregivers and their families.

In AARP's snapshot of caregiving in America, they estimated that as many as 42.1 million people in 2009 were providing some sort of help with activities of daily living to an older adult. That number jumps about 50% when you look at all the people engaged in some sort of caregiving at any point during the year: 61.6 million people. And these individuals are offering their support as unpaid caregivers. If this were an "industry" instead of a voluntary contribution of time and energy, it would be generating an estimated \$450 billion a year, an increase of about 20 percent over the prior year.

Family caregiving is the single biggest contribution to an older adult being able to stay in their own home and age in place. Caregivers do everything from transporting the older adult to and from medical appointments to coordinating the services of other medical providers, managing multiple medications and advocating on behalf of their family member. It takes time and weighs heavily on the caregiver who still must balance caregiving potentially against a full-time job, parental responsibilities and a marital partner. Caregivers often don't get much explicit attention as part of the team or for their tremendous contributions.

### The AARP article notes that:

*“...ignoring family needs can place caregivers at risk for negative health consequences that can jeopardize their ability to provide care in the home. Interventions that include an explicit focus on assessing the needs, strengths, values, and preferences of family caregivers are important. Such interventions can be designed to reduce burdens and health risks that can impede a caregiver's ability to provide care, prevent unnecessary hospitalizations, and prevent or delay institutional care. Strategies to strengthen and sustain caregiving families will enable them to continue as caregivers, and will reduce costs.”*

It really comes back to three points I cannot repeat often enough. One, caregivers' contributions need to be appreciated by the entire family who benefits. Two, the whole family also needs to help in caring for the caregiver. Three, it takes a village for all of the above.

## CAREGIVERS CAN GET THE BLUES



Caregiving has some obvious costs in time, money and other resources, but one cost that does not get enough attention is the toll it can take in the form of caregiver depression. As a geriatric care manager, one of my principal points of contact is the member of the family who has been delegated or who has defaulted into the role of caregiver for an older adult or other person with special needs. And while we are all about the business of planning for the older parent, it also is critical to address the individual who is providing the care. The sad irony is that the caregiver feels guilty about even talking about the dark cloud that seems to be hanging over them, guilty that they do not feel the fulfillment of taking care of the parent who once took care of them. This, despite the fact that the caregiver of an older adult more often than not has other family responsibilities already.

More than 20 million Americans suffer from depression, and caregivers are more likely than the average person to get something that is not just the "blues." We all recognize the time and work that a caregiver

## CAREGIVERS CAN GET THE BLUES

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puts in to help an older adult, but what we may not fully realize is that they also may be giving up the time they would have been spending with their spouse or significant other. Or the nights out with friends and acquaintances, the moments during any given week that would give a break from the routine, make them laugh or fulfill them. Today's caregivers are part of the sandwich generation and have not yet fully launched their children and are also full time employees. Now, add to those the responsibilities and worries of caring for mom or dad and you have a recipe for depression.

**If you or someone you know is a caregiver, I recommend the following strategies:**

- ✓ Include you; make time each day to do something that delights, relieves or distracts you.
- ✓ Make lists; prioritize your caregiving duties, make lists and you will see you are making progress even when there remains more to do.
- ✓ Request help; appreciate that it is gratifying to the others whom you may ask for help to be of help to you and your elder.
- ✓ Leverage your abilities; the others who can give you respite are actually better equipped for what you may delegate than you are, a win-win.
- ✓ Make yourself laugh; hard work like caregiving can seem devoid of fun, so you have to take time to have some fun.
- ✓ The American Medical Association has a self-care questionnaire: [http://www.ama-assn.org/resources/doc/public-health/caregiver\\_english.pdf](http://www.ama-assn.org/resources/doc/public-health/caregiver_english.pdf). The National Mental Health Association has a screening checklist: <http://depression-screening.org>

## SIGNS OF CAREGIVER BURNOUT

As a Geriatric Care Manager, I have seen caregiver "burnout" and the toll that caregiving can take on a loved one. When I am working alongside a family member who shoulders a big share of the care for an older adult or someone with special needs I look for signs of potential burnout. Quite often, however, caregivers try to hide what they are feeling as a response to the stress of their physical and emotional workload. Trying to hide the signs and feelings only exacerbates the issues.

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## FINDING CAREGIVER SUPPORT SERVICES

At the center of a lot of what can be done for the caregiver is a very simple philosophy: “Don’t try to do it all alone.” As a Geriatric Care Manager, this is where I often get the call. The caregiver or someone close to the caregiver needs somebody to help make decisions, take over some of the workload, stand up for an elder or other individual with special needs or counsel the caregiver on self-care.

There are other resources that can provide decision-making support, take on some of the caregiving responsibilities, advocate for an elder or caregiver and offer professional counsel on just coping. There are services to help caregivers in most communities, and the cost is often based on ability to pay. Look to programs such as adult day care centers, home health aides, home-delivered meals, respite care, transportation services, and skilled nursing.

Having talked about the stress of caregiving, I think it is really important to distinguish stress from burnout. Experiencing stress is not the same as burnout, although stress that is not relieved can certainly lead to burnout. Let me give you a few contrasts and then some signs to look for in a family member who is the caregiver or even in yourself if you have taken on the role of caregiver:

1. You are stressed if you are “hyper-involved,” but burnout encourages disengagement from others.
2. You are stressed if you feel in emotional overdrive, but burnout makes all your emotions duller.
3. Stress can lead to anxiety about doing enough, but burnout more typically results in depression.
4. Stress can sap your energy, but burnout depletes your motivation or your hope.
5. Stress may induce a sense of urgency about all that you have to do, but burnout results in the detachment of depression.

I have a client who is a husband caring for his spouse who has dementia. It is exhausting work, he admits, but he is quite dedicated to her. His response is to take daily breaks to work-out at a fitness center in his residence. It gives him a chance to recharge as well as the physical capacity to do the next shift. One of my associates describes it as “taking care of yourself so that you are better able to care for another.”

Check out some of the recommendations of a group called “HelpGuide” at [http://helpguide.org/mental/burnout\\_signs\\_symptoms.htm](http://helpguide.org/mental/burnout_signs_symptoms.htm). They sum up their approach simply in three R’s:

- ✓ Recognize-identify the symptoms
- ✓ Reverse-address the stress and/or seek help
- ✓ Resilience-take care of your emotional and physical well-being.

Charlotte Bishop, MS, CRC, CCM, CDMS, LCPC is a Geriatric Care Manager and founder of Creative Case Management, Inc. [http://www.creativecasemanagement.com/elder\\_home.aspx](http://www.creativecasemanagement.com/elder_home.aspx), certified professionals who are advocates, resources, counselors and friends to older adults and their families.

At the center of a lot of what can be done for the caregiver is a very simple philosophy: “Don’t try to do it all alone.”

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## CCM, INC. CAN BE THERE WHEN YOU CAN'T

We are the professionals who help families who are caring for older adults (geriatric care management) or others with special needs. Our professional geriatric care managers and special needs case managers can be your eyes and ears when you simply cannot. You can count on us to help you manage both your care-giving responsibilities, and those of your family and your work that cannot be ignored...or postponed. Some of our clients refer to us as their Sister in Chicago<sup>SM</sup>.

We serve Chicago's North side and the North, Northwest and West suburbs as well as Central Illinois.

[www.creativecasemanagement.com](http://www.creativecasemanagement.com)

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