

## What Every Dementia Caregiver Must Know

by Kim Warchol, OTRL, DCCT

With over five million people in the US with Alzheimer's/dementia today, it is of vital importance to empower the family and professional caregivers with support and dementia care skills. Providing care that yields positive outcomes for both the person living with Alzheimer's/dementia and the caregiver is very important and challenging.

### Obtain the necessary help and support

Whether a family or a professional caregiver, it is important to establish a dementia management team for expertise and emotional support. For example, the family caregiver should never feel or be alone. An important first step is to join a support group.

The family caregiver should use the many professional resources available to receive critical advice and guidance throughout the journey. For example, there are Alzheimer's diagnostic centers available to make a diagnosis and to provide medical treatment. In addition, that physician or a primary doctor may be able to refer an Occupational Therapist (OT) who specializes in dementia care. The OT can perform an assessment of the person with Alzheimer's/dementia, analyze the caregiving and living environment situation, and provide ideas and education to improve safety, functional independence, and quality of life.

Family and professional caregivers often experience stress and feelings of being overwhelmed or uncertain. The emotional support, advice, and knowledge derived from a team are critical for all caregivers to be as successful and stress-free as possible.

### Dementia Capable Communication

The caregiver must understand how to communicate with the person with dementia. Simple communication modifications are necessary to increase understanding such as:

- Wait for a response
- Take a complex situation and make it simple by breaking it into one-step directions



- Use visual or hand over hand cues with words

### Dementia Capable Behavior Management.

The caregiver must know how to reduce the prevalence of negative behaviors. This begins with knowing that most negative behaviors expressed by a person with dementia have a reason or trigger and that behavior is most often simply a communication of an unmet need. Typical reasons for a negative behavior may be unmanaged pain, loss of control, fear, or boredom. If the behavior is not causing an emergency, it is important for caregivers to take time and look for patterns that lead to identification of the likely reasons behind the behavior. When the trigger is addressed, it can reduce or eliminate the negative behavior.

### Accept what is, celebrate the moments, and know that you are making a difference

Often, caregivers struggle to find the value and meaning of their interactions, care, and relationship. I believe this is so often the case because caregivers focus too much on what has been lost to the disease instead of what remains.

- It is true a person with dementia may reach a stage in which they don't remember visitors, but it doesn't mean the moments spent during the visit weren't special and therefore valuable to creating quality of life.

*Continued on page 2*



## Mission

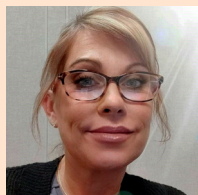
To provide a comprehensive and coordinated system of services designed to promote the independence and dignity of older persons and their families in Muskegon, Oceana, and Ottawa – a mission compelling us to target older persons in greatest need but to advocate for all.

## Caregiver Support Staff



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## Go Green or Stop Receiving Newsletter

If you would like your copy of the *Caregiver Link* emailed or would like to discontinue receiving our newsletter, simply send your request to:  
kport@seniorresourceswmi.org.

*What Every Dementia Caregiver Must Know, continued from page 1*

- It is true that at some point a person with dementia may not be able to play a dice game with the same skill and expertise they once had, but it doesn't mean they wouldn't enjoy sitting at a table hearing the familiar sound of the dice rolling, or throwing the dice while others clap and encourage.
- It is true a person with dementia may not be able to plan and tend to the garden in the expert way of days gone by; it doesn't mean they wouldn't enjoy planting with help, while feeling the sunshine on their face and hearing the birds sing.

There is a fulfilling, rich relationship that can occur and be maintained between a person living with Alzheimer's/dementia and their caregivers. ❖

## Caring for an aging spouse presents unique challenges

*by Carol Nelson, RN, BSN, MBA*

*C*aring for an aging spouse can often be the most challenging decision ever made in a marriage. It forces the couple to have to rewrite the relationship's expectations, which can be hard to do after years of partnership.

While one spouse has taken on the role of caregiver considering the waning health of their partner, the other spouse feels guilty at being a burden. The illness or age-related decline can overtake the relationship causing the caregiving spouse to be ignored or overlooked in favor of the ill partner at a time when they need assistance the most.

Recent studies suggest that while a spouse will protect and care for his or her partner, they often report more depression, anxiety, and financial loss than other married couples of the same age but without the medical issues. Because of the sudden nature in this shift in relationship duties, the caregiving spouse also is not prepared for the mental toil this change can have on their emotional well-being.



But there are ways that spouses can prepare each other for this possibility and ways the caregiving spouse can cope if the situation has already reached this point.

### Have a conversation about aging

When a marriage is new, thoughts of aging are at the backburner as the couple plans a new life together. Then comes the living – buying houses, raising children, and working. These things may get in the way of having a conversation about what is expected should the day come when one spouse must care for another. However, making time to have this discussion can save heartache later. Planning for aging care is just as important as planning for retirement or death. Talk to your spouse about this as part of other planning activities.



## Get needed help

The burdens of taking care of a spouse can build, making it harder to have patience with daily tasks, doctor's appointments, and unexpected issues. This is when the spouse needs a break. When possible, asking a friend or family member to help, or even hiring a professional caregiver for a short period of time can give the caregiver a much-deserved break to recharge. Seeking advice on how to cope with both the change in the relationship and with the actual process of caregiving is also recommended. Join a group that caters to spousal caregivers, talk with a mental health expert, or bring children or other family members into the discussion to help alleviate the burden.

## Allow time to accept the relationship's changes

Certainly, the caregiving spouse must manage any medical care their husband or wife needs immediately, but the caregiver also needs time to process the relationship's new roles. In much the same way people need time to grieve the death of a loved one, a new caregiver needs time to mourn the loss of their former lifestyle. Call on family or friends to commiserate or lend an ear. If necessary, consult a doctor or support group for help in accepting this huge change.

## Become informed about the spouse's physical needs

In addition to the aging process, often the spouse has other ailments that need treatment. Learning more about the condition affecting the partner will make the caregiver better able to handle any issues that come up during care. Talking to the spouse's doctors and researching the condition on trusted medical websites like the Mayo Clinic or disease-specific sites like the Alzheimer's Association will arm caregivers with knowledge. Many of these sites also have links to local support groups.

## Include the ill or aging spouse in decisions when possible

Many times, the spouse in need of care is still mentally agile and can help with decision-making even if they are too physically ill to act. Don't assign the ill spouse to a passive role simply because they require care. If the aging spouse is able, plan events as a couple. An indoor date night with dinner and a movie, playing board games or participating in an activity the couple enjoyed together before the illness can remind partners they are still a couple even if the dynamics have changed.

## Retain the aging spouse's dignity

Maintaining the relationship as a couple should include acknowledgment that the ill husband or wife is still a human. Allow the spouse to do tasks they can perform and don't expect to do everything for them. If there are tasks the aging spouse can still do, they should be given the opportunity to do them. Some spouses resent or feel guilty that their partner is doing so many chores for them, so allowing them the dignity to do what they can is encouraged.

The key to caring for an aging or ill partner is to realize that this is no longer an isolated situation and help is available. A serious illness or aging issues should not rock the foundation of a marriage. Find comfort in the knowledge that being a devoted partner to an aging or ill spouse until the very end is the very embodiment on which most marital foundations were built. ❖



In 1914, President Woodrow Wilson proclaimed the second Sunday in May as a day of public expression of our love and reverence for the mothers of our country making it an official US holiday.

## April's Website

[www.caregiver.org](http://www.caregiver.org)

## Quotes

"You have two hands. One to help yourself, and one to help others."

*Audrey Hepburn*

"Doctors diagnose, nurses heal, and caregivers make sense of it all."

*Brett H. Lewis*

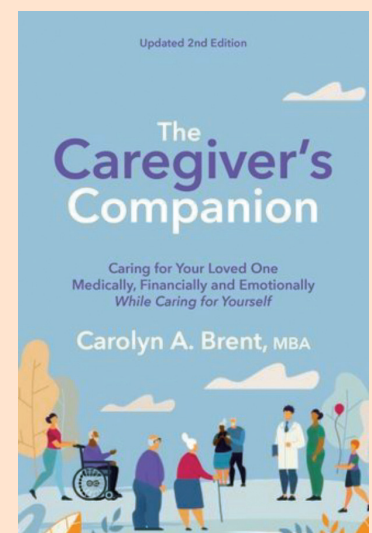
To the world you are a MOTHER but to your family you are the WORLD.

## This Month's Book

### *The Caregiver's Companion*

*by Carolyn A. Brent, MBA*

Everything you need to know to ensure that your elderly loved one is being properly cared for.



## Caregiver Burnout

by M. Ross Seligson, Ph.D., P.A.

Being able to cope with the strains and stresses of being a caregiver is part of the art of caregiving. In order to remain healthy so that we can continue to be caregivers, we must be able to see our own limitations and learn to care for ourselves as well as others.

It is important for all of us to make the effort to recognize the signs of burnout; in order to do this we must be honest and willing to hear feedback from those around us. This is especially important for those caring for family or friends.

Too often caregivers who are not closely associated with the healthcare profession get overlooked and lost in the commotion of medical emergencies and procedures. Otherwise, close friends begin to grow distant, and eventually the caregiver is alone without a support structure. We must allow those who do care for us, who are interested enough to say something, to tell us about our behavior, a noticed decrease in energy or mood changes.



Burnout isn't like a cold. You don't always notice it when you are in its clutches. Very much like Post Traumatic Stress Syndrome, the symptoms of burnout can begin surfacing months after a traumatic episode. The following

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## Avoiding Drug Interactions

According to the American Society of Health-System Pharmacists, more than 34% of seniors take medications prescribed by more than one physician and 72% take medications that were prescribed more than six months ago. Caregivers need to be aware of the potential for drug interactions. Interactions occur when medications don't work in tandem with one another and instead one or both of the drugs adversely affect health.

Prescription and over the counter (OTC) medications, as well as herbal remedies and food interactions, are concerns. Drug reactions are just as critical as interactions since they can also cause problems.

### Medication-Medication Interactions:

Drug interactions are a concern for people since as they age, they tend to take even more medications. Common OTC medications can cause serious drug interactions as well. It is critical to take a complete list of medications to both your doctor and your pharmacist.

Pharmacists train in medication and specialize in learning about interactions, which is why experts suggest using the same pharmacy each time a prescription is filled. The pharmacy keeps records and flags the account for possible drug interactions. Bring a record of any OTC medications your loved one takes so that your pharmacist can have a complete record of medications given at home.

Almost all pharmacies provide printed leaflets with each prescription. Read these leaflets carefully and pay close attention to the side effects and possible drug interactions. You can call your doctor or pharmacist with questions.

Depending on the condition being treated, your physician may suggest not taking OTC medications due to possible interactions. Make sure your medical provider is aware of all health conditions which may affect the medications.

### Herbal Remedies:

Just because an herbal remedy touts that it is all-natural does not mean that it is safe. Some herbal products can cause dangerous interactions with medications. Do not take an herbal remedy for the same condition for which medication has already been prescribed unless approved by the doctor. List herbal remedies along with other medications that you are taking to be certain that the doctor has an accurate picture of everything that is taken at home.

Herbal remedies often make claims on the packaging that have not been safely evaluated by the Food and Drug Administration. If you feel it necessary to take an herbal remedy, consult your physician first.

### Food-Drug Interactions:

Certain foods can also affect medications, usually in ways that the medicine is absorbed throughout the body. The pharmacy may have more information for specific medications.

- Food can slow the absorption of some medicines throughout the body.
- Meals high in carbohydrates can adversely affect absorption rate of some medications.
- Some medications need food to help it absorb for the body's use.



### **Alcohol-Drug Interactions:**

The National Institute of Alcohol Abuse and Alcoholism estimates that 25% of emergency room admissions may have alcohol-drug interactions as a component of the underlying problem. The elderly are especially at risk for this type of interaction since they consume more than 30% of all prescription medications in the U.S. today and the risk for alcohol abuse is also significant.

Alcohol intensifies the effect of some medications, such as sedatives or pain medicines. Some medications increase the effects of alcohol, causing dizziness, drowsiness, inability to control balance or walk properly, and more. Alcohol can prolong the absorption of the medication, risking more side effects in the body. It can also have the opposite effect by prolonging the metabolizing of medication the bloodstream, rendering the drug less effective.

### **Drug Reactions:**

There is also the question of how a person will react to a medication. Side effects are possible with any medication since there are many different types of people and diseases.

- Keep a diary of any reaction that seems unusual:
- When was the medication given?
- How long did it take to notice the reaction?
- What is the nature of the reaction?
- Does it seem to get better or worse as time goes by?
- Is this a known side effect of the medication?
- How much discomfort does it cause in the patient?
- Your physician may suggest other areas to observe.

By keeping a comprehensive diary of reactions, you can determine whether this is a true drug reaction or a symptom of the underlying disease, or even a new one that may be developing.

Be certain that you maintain open lines of communication with both the doctor and the pharmacy in order to better provide care for your loved one.

*Taken from an article from Caregiver.com ❖*

*Caregiver Burnout, continued from page 4*

are symptoms we might notice in ourselves, or others might say they see in us. Think about what is being said and consider the possibility of burnout.

- Feelings of depression
- A sense of ongoing and constant fatigue
- Decreasing interest in work
- Decrease in work production
- Withdrawal from social contacts
- Increase in use of stimulants and alcohol
- Increasing fear of death
- Change in eating patterns
- Feelings of helplessness

Strategies to ward off or cope with burnout are important. To counteract burnout, the following specific strategies are recommended

- Participate in a support network.
- Consult with professionals to explore burnout issues.
- Attend a support group to receive feedback and coping strategies.
- Vary the focus of caregiving responsibilities if possible (rotate responsibilities with family).
- Exercise daily and maintain a healthy diet.
- Establish “quiet time” for meditation.
- Get a weekly massage.
- Stay involved in hobbies.

By acknowledging the reality that being a caregiver is filled with stress and anxiety, and understanding the potential for burnout, caregivers can be forewarned and guard against this debilitating condition. As much as it is said, it can still not be said too often—the best way to be an effective caregiver is to take care of yourself. ❖



## Join us for Senior Action Week during Older Americans Month

May is Older Americans Month, and in Michigan, it is Older Michigianians Day and Senior Action Week, May 9-13. Senior Resources, along with other Area Agencies on Aging and aging network community partners, is working diligently with elected officials to make sure they understand critical needs of all older adults in Michigan.

Older Americans Month's theme this year is Age My Way—how older adults can plan to stay in their homes and live independently for as long as possible. The Administration for Community Living leads the nation's observance of Older Americans Month to honor and recognize older Americans during May to encourage and recognize the contributions made by older adults in our communities. We honor their time, experience, and talents, with a special focus on advocacy. Planning, participation, accessibility, and making connections all play a role in aging in place.

In Michigan, Senior Action Week focuses on five platform issues involving priority issues for the FY2023 state budget:

- Support and Strengthen the Direct Care Workforce
- Rebalance Community-Based Long-Term Services and Supports
- Expand Access to MI Choice
- Increase Access to Home and Community-Based Services
- Bridge the Digital Divide for Older Adults

On Wednesday, May 11, there will be a livestream event at 11 a.m. Legislators will speak on issues impacting Michigan's older adults. You can join the livestream event by phone at 1-301-715-8592 or via the web. Contact Lisa Tyler, [lyler@seniorresourceswmi.org](mailto:lyler@seniorresourceswmi.org) or visit [www.4ami.org](http://www.4ami.org) to get the link or find out more about Older Michigianians Day. ❖

## How is Hospice a Good Thing?

by Tami Vajskop RN CHPN

She looked intelligent, tired, strong, defiant, and wounded. She opened the front door enough to let me see her while tightly guarding the entrance. She said, "My friend told me hospice was a blessing—a 'good' thing. How in God's name can my husband needing hospice be a 'good' thing!"

I hear that question often. There is no good answer, because the truth is you can't possibly know what you need until you've been through it. Her husband was only 49 years old with a very aggressive brain tumor. He was a vibrant, handsome, loving father, and a self-made man with a thriving business. A year ago, while ordering a sandwich with his daughter, he suddenly could not understand the words on the menu. A week later, he had difficulty walking, then diagnosis was made, treatment took place, and after a long year, he made the decision to talk about Hospice care.

We were still standing in the doorway as she waited for an answer to her question. Somehow the idea of asking me in was acceptance. I did not move. Her eyes stayed fixed on mine.

"Needing hospice is not a blessing," I said quietly. One of her eyebrows lifted a bit, and she tilted her head.

"When managing the disease is too much to do alone, when you're done with aggressive treatment, you need help to manage the symptoms, and you want to spend every minute making the most of each day—then it's time to talk about hospice. Needing us is not the blessing. Having access to us is. Having us there with you, walking these next months with you so we can help you, your children, and family navigate what is happening and what is to come, then supporting you for a year after as you grieve, remember, and rebuild—that is the blessing."

She stared at me for what seemed like an hour. Her eyes filled with tears and so did mine. She opened the door and motioned me in.

He was at the kitchen table as we came in. "I suppose you heard that," she said to him and smiled. "Sorry if I was rude," she said to me. He tried to talk but struggled. It's called expressive aphasia. You know what you want to say, but the words make no sense. He smiled and put his hand on mine.

"Hi Greg, I'm Tami," I said to him. "Do you want me to talk to you and your wife about Hospice services today?" I asked. His hand was still on mine. He smiled and nodded yes.

We began.

For three months Greg was able to stay home with his family. We were able to get the oldest kids home from college, help them keep their Christmas traditions, and work with his mother and father so that everyone was included and enjoyed precious time together. His symptoms were well managed.

About the fourth month we had what we call a crisis morning. The family was exhausted, and the idea of Greg dying at home was concerning to the family who planned to remain in the house after he passed. He needed intensive management to control new seizure activity.

We transferred Greg to our inpatient unit. He had around the clock expert care, and we were able to work with our spiritual and bereavement teams to help his children, his wife, and his parents come to peace with his changing condition

When terminal illness invades, we all ask ourselves the same questions, and agonize over the choices that we have made on someone's behalf because we love them. Because we want to do everything possible. Because we want them to fight.

We have so many incredible medical options available to us with new treatments and trials unfolding every day. And while it is wonderful to have so many treatment options, when a person is more miserable with treatment than they are with the actual disease, it's time to re-address the options.

Every patient knows when they have had enough. They want peace. They want control. They want the dignity of choice. When a patient decides to keep going beyond that time, it has little to do with what they really want. At that point, be assured, they are doing it for their loved ones who are begging for them not to stop. Hospice is not giving up. I have never had a patient say, "I wish I had waited longer to call you." I have had many say, "Oh my God, I wish I had called you sooner."

I do this for a living, and when it was time to care for my own mother at home she chose Holy Family, and even though I was not her hospice nurse, I was her caregiver. I made promises to her as her daughter about care choices, that as a nurse I might have questioned. Her daughter promised those things to her – not her



daughter the nurse. My job was to make sure her wishes were respected. I kept those promises even though there were moments, as a clinician, that I struggled with some of those decisions.

Hospice is giving the gift of a dignified choice. It was painful when my mother decided she wanted to stop

treatment, but it was robbing her of her strength and comfort with no promise of a cure.

Hospice care is a treatment choice. We do have patients who choose hospice care and stabilize. We have patients who start hospice and then change their minds to pursue treatment. That's always an option. A patient can revoke the benefit and choose it again when they are ready. So how do you know when to call hospice?

Ask yourself: who is the patient? What kind of spirit do they have? How do they want to spend the time they have left? Those are the real questions. Choose a hospice provider that you trust. Gather information, ask the questions you have on your mind, and remember that the most loving thing anyone can do for their loved one is to walk the journey with them and respect their choices with every step. ❖

## New Support Groups Added

Senior Resources is pleased to share the addition of two new caregiver support groups, in Montague and at Four Pointes Center for Successful Aging in Grand Haven. That brings us to four weekly groups, with plans for more in the future.

Caregiver support groups are safe spaces for caregivers to share concerns, offer suggestions and ideas, vent, and offer support and encouragement to other caregivers. Those attending may feel less lonely, feel validated by experiences, and gain connection, support, and friendships. Studies show that caregiver support groups can help improve the quality of life for the caregivers.

You can attend regularly or drop in when it is convenient for you. Respite help may be available by contacting one of our caregiver support specialists.

### **Every Tuesday – 1-2:30 p.m.**

The Book Nook, 8744 Ferry St.,  
Montague 49437

### **Every Wednesday – 1-2:30 p.m.**

Tanglewood Park, 560 Seminole Rd.,  
Muskegon 49444

### **Every Thursday – 1-2:30 p.m.**

Four Pointes Center for Successful  
Aging, 1051 S. Beacon Blvd.,  
Grand Haven 49417

(in the strip mall behind Panera Bread)

### **Every Friday – 1-2:30 p.m.**

via Zoom.

For more information about any of these support groups or for respite vouchers, please contact:

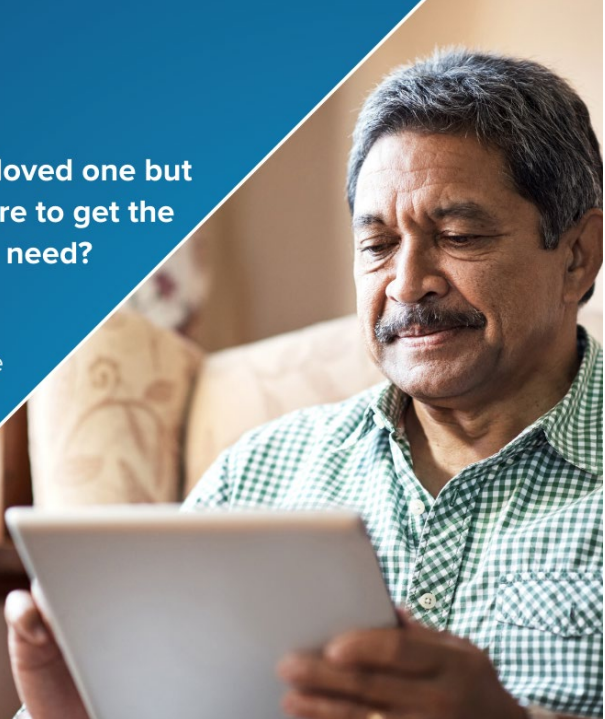
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Caring for your loved one but don't know where to get the information you need?

Start with this free caregiving resource

Free caregiving resource!



Practical advice to care for your loved one.

Trualta's Caregiver Portal shows you how to manage aging at home

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