



You are **not** alone...

Education on Caring for
the Patient with Dementia



Join Dr. Buenaver for the first part of the series Family Involvement in Dementia Care: “Talking with Providers”

Interacting with many different health providers can be frustrating for many reasons:

1. Miscommunication from use of medical terms
2. Fast pace of medical environment
3. Conflicting priorities between family and provider

Working as a Team

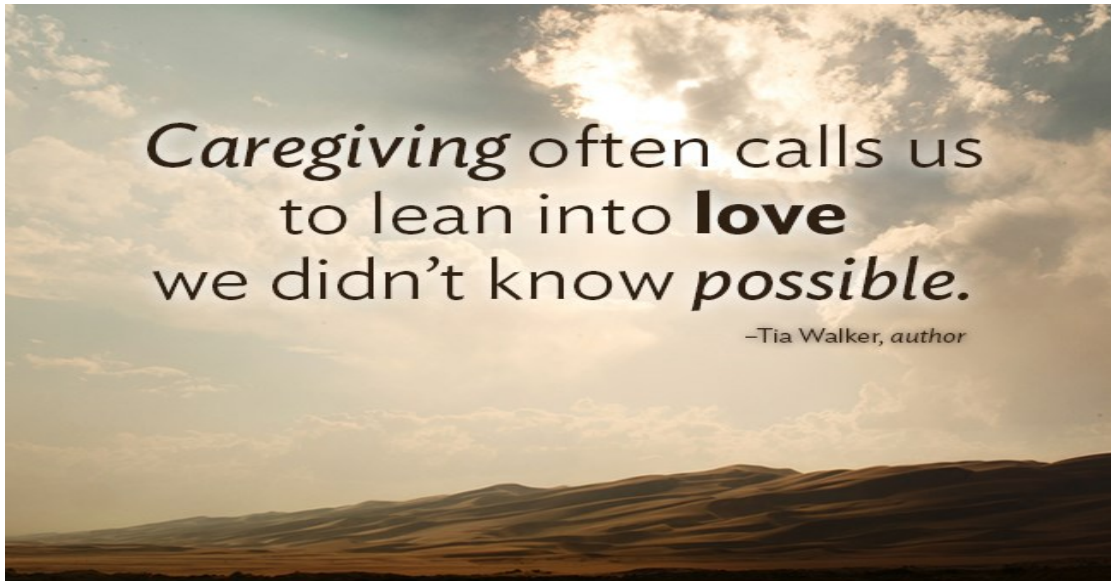
Partnerships in Care Mean:

1. Good communication
2. Asking questions or for explanations
3. Bringing up concerns with routines or treatments
4. Being prepared

What is the Concern?

The reason for talking to the provider is also key for:

1. Establishing Care—Building a relationship takes time and effort
2. Change in Status—Emerging health issues to discuss or treat
3. Behavioral Symptoms—Discuss possible interventions
4. Provider Challenges— Discuss barriers or approaches to resolve
5. Questions—Discuss support services and resources available
6. Routine Visits—Primary care or care conference



What is Your Role in the Conversation?

As a caregiver:

1. Are you the primary family caregiver who makes most decisions?
e.g., husband, wife, partner, etc.
2. Where does your loved one live now?
e.g., at home with you or others, supervised setting?

As a proxy decision maker:

1. Are you now the proxy decision maker for your loved one?
2. Is your loved one able to accurately report on symptoms, experiences or care needs?
3. Are conversations a mix of your and their input?

Having the Conversation

Check their understanding of your concern:

1. “What have you heard me saying?”
2. “How can I help you understand my position?”
3. “What don’t you follow?”

Remember: What you think you said, and what they “heard” don’t always agree!



Having the Conversation

Monitor your non-verbals:

1. Tone of voice
2. Facial expressions

Avoid sending a message you don't really mean!

Ask questions:

1. "I don't know what that means. Can you please explain?"
2. "I want to make sure I understand. Could you explain more?"
3. "What is the goal of this medication or care plan?"
 - ◆ What does it do?
 - ◆ What are the side effects?
 - ◆ How much does it cost?

Be open and honest; don't hold back

Tips from family caregivers:

1. Prepare in advance.
 - ◆ Think about questions you may have.
 - ◆ Review provider's website for frequently asked questions.
2. Ask how to follow up if you have questions after the appointment.
3. Take notes (keep a notebook for the information).
4. Ask the provider what other people ask in this situation.

Be Prepared

Make a list of discussion points:

- ◆ Behaviors
- ◆ Medications
- ◆ Concerns about your health or stress level

Set Priorities: Keep in mind: What is the goal?

What questions do you find difficult to bring up with providers?

How do you feel these topics can best be discussed openly?

Summary:

Things to consider when talking with providers:

1. Being prepared is key
 - ◆ What do you want to happen?
 - ◆ How can you best and concisely explain it?
 - ◆ What background information will help?
2. Be open and honest
3. It is your right to:
 - ◆ check for understanding
 - ◆ ask questions
 - ◆ explore choices
4. If needed, excuse yourself and regroup



Overcoming Family Caregiver Stress

The job of caregiving, while a worthwhile and rewarding endeavor, is loaded with stress and requires an incredible amount of patience and understanding. Some loved ones require round-the-clock care, giving little rest to their caregiver.

Unfortunately, stress among caregivers is extremely common. Caregivers often try to do everything by themselves, which eventually leaves them worn out and unable to fully attend to everything they are expected to do. Furthermore, ignoring the symptoms of stress can affect physical and mental health and lead to burnout, and make it impossible for the caregiver to continue caring for their loved one.

Tips For Overcoming Caregiver Stress

Build a Support Network

One of the biggest sources of stress is the inability to escape caregiving responsibilities. Although many caregivers attempt to go it alone, they can be better caregivers if they utilize all available support services. If anyone, such as friends and family, has mentioned they will help the caregiver when needed, those names should be put on a list and utilized from time to time. Needs should be stated very specifically.

Exercise

Exercise releases endorphins that can help make caregivers feel better. This doesn't mean joining a gym – caregivers have precious little time to engage in traveling back and forth – but they may be able to fit in a brisk 10-minute walk while the one being cared for is napping. Even when providing care, caregivers can sneak in a little exercise by gardening or following along with a short exercise video.

Get Enough Sleep

The first key to a good night's sleep is creating at least a half hour of downtime before bed. The primary caregiver may be able to enlist other family members to take over so the caregiver can unwind. Developing a sleep routine helps; going to bed and getting up at the same time everyday keeps everything on schedule. Be sure bedrooms are conducive to sleep – the room should be dark, cool, and quiet. Avoiding alcohol and caffeine encourages more restful sleep. Caregivers should not discount the power nap – if the one being cared for is napping, caregivers should consider napping at the same time.

Stay Connected

Connecting with other people is extremely important. Most caregivers feel socially isolated and disconnected with the world as their tasks become all-consuming. If possible, the caregiver should arrange to get out for a day or even just an evening with friends. If that kind of connection isn't possible, joining a support group may help because caregivers can connect with people who are in similar situations.

Reprinted from <https://adrenalfatiguesolution.com/caregiver-stress/>

How to Make Caregiving at Nighttime Easier

Frequent bathroom use

If a loved one formerly slept through the night but has begun getting up to use the bathroom frequently, you might want to consult his or her doctor to make sure the senior does not have a urinary tract infection or some other treatable condition. If an infection has been ruled out and the senior simply needs to empty his or her bladder frequently at night, then you might streamline the process by adding a portable bedside commode.

Insomnia

Insomnia occurs more frequently in seniors, though researchers aren't quite sure why. Sometimes medications can trigger insomnia, so if a senior family member suddenly begins having trouble sleeping through the night you might want to consult his or her doctor for an evaluation.

Alzheimer's disease

Many seniors with Alzheimer's or a related dementia engage in rummaging behavior during the night. While you may not be able to eliminate this behavior entirely, you can strive to manage the situation and get the senior returned to bed creating a safe rummage bag, drawer or even room (like a walk-in closet). The rummage bag should include the types of item the senior seems to enjoy sorting through. Often this includes clothing, like socks. Observe the senior's behavior to get a sense of what types of objects they like to handle, and include these in the bag.

You give so much through caregiving, but you shouldn't have to sacrifice your sleep. Family caregivers who experience chronic sleeplessness face a higher risk of developing cardiovascular disease and other medical conditions. By using the above tips to manage a senior loved one's waking episodes as efficiently as possible, you create more healthy sleep opportunities for everyone.

Reprinted from <http://www.everythingzoomer.com/tips-make-overnight-caregiving-easier/>



The Caregiver's meeting is held the 3rd Thursday of each month at 2:30pm, Building 24 in the Recreation Hall of the hospital. We meet informally at 2:00 pm for support and snacks.

Do you have a story you would like to share? Are there questions you would like answers to from other caregivers? Would you like to know how other caregivers handle difficult situations? If so, approach Dr. Buenaver at the meeting. We will be gathering at 2:00 pm, 30 minutes before the meeting starts.

Join Dr. Buenaver on September 21st at 2:30pm for the first part of the series Family Involvement in Dementia Care.

This material is funded in part by HRSA 1 U1QHP28731-01-00 Interprofessional Strategic Healthcare Alliance for Rural Education, and is the result of work supported with resources and the use of facilities at VA Eastern Kansas Health Care System.

Presently we have a program for education on caring for the Veteran with dementia. It includes a monthly newsletter which can be mailed to your home, or if preferred emailed to you. You are welcome to bring the veteran to these meetings. Due to technical issues, we can't accept incoming emails at this time.

You are not alone.

