

The Caregiver Link

Volume 17 Issue 3

March, 2017

QUOTES

“Some of us think holding on makes us strong but sometimes it is letting go.”

~Unknown

“Strength does not come from what you are capable of doing. Strength comes from overcoming the challenges which present difficulties in your way.”

~Dr Anil Kumar Sinha

“You may encounter many defeats, but you must not be defeated.

In fact, it may be necessary to encounter the defeats, so you can know who you are, what you can rise from, how you can still come out of it.”

~Maya Angelou

A Deep Dive into Sundowners

“Just shoot me,” Steve said to his wife, “if I am ever diagnosed with Alzheimer’s Disease.” Of course, she has no intention of doing this, but it shows how Steve ~ and much of the population ~ feel about this dread disease. Yet Alzheimer’s remains the sixth leading cause of death in this nation where approximately five million people suffer from it.

Recently, the Muskegon Chronicle published a fine, if discouraging, article on the subject. It stated that, “Decades of research have not produced a single drug that alters its (Alzheimer’s) course.” Researchers tell us they now believe that ~ like cancer ~ the cure will not be a “magic bullet” for all patients but a matter of choosing the right solutions for each individual.

With this in mind, it makes sense to tackle methods to treat various symptoms to make life easier for both patient and caregiver. Sundowning is one of those conditions that occur in about 20% of Alzheimer’s patients. As light fades from the day, caregivers notice mood changes in their loved ones; typically negative ones. Agitation is often predominant in these patients, marked by anger, anxiety, fear, sadness, stubbornness, even paranoia. Behavior can also change, with your loved one striking out at others, hiding things, suffering from hallucinations, wandering or pacing, rocking or crying.

Again, researchers are not sure what causes sundowning. Why does it occur ~ with few exceptions ~ only at sundown? Why does it afflict only 20% of Alzheimer patients? How can we help our loved ones?

Many scientists believe sundowners is caused by dementia disturbing the patient’s circadian rhythms (fancy talk for biological clock). This seems likely when you think about it. For example, researchers have found teens are biologically predisposed to stay up late at night and sleep late in the morning. However, our expectations of teens say they should get up with the chickens and go to school. Goodness

knows their behavior changes when they are sleep deprived!

One thing is quite clear. Most of the symptoms of sundowning can be considered to be different ways of expressing fear.

Consider Martha. She lived in assisted living comfortably for several years. Some of her relatives, however, felt sorry for her “stuck there for Thanksgiving.” They arranged to take Martha to one home for a late afternoon dinner. They sat her at the table in an honored seat with a beautiful spread before her.

Despite the love and good humor surrounding her, Martha became very agitated. “Where’s Bob?” she kept asking. Of course, her long dead husband was nowhere to be found and she became more and more upset. It was hurtful to many of those assembled that Martha had no memory of any of them. They were, in her mind, complete strangers who had kidnapped her and placed her in a totally foreign situation. Plus, it was getting dark outside and Martha was scared to death!

Of course, no one had sinister motives. They simply didn’t understand the mechanics of Alzheimer’s Disease, a fact that transformed an act of kindness into a traumatic situation for a loved one.

Fear makes sense. The patient has lost so many of the coping skills that had traditionally rescued her from bewildering situations. Dementia patients lack the language skills to ask questions and express preferences. The cognitive ability to figure out new situations is missing and patients may confuse dreams with reality. Acute hearing and sight may be compromised, giving faces, places and things a nightmarish cast in the lengthening shadows of sundown. Throw in the fatigue to be expected at the end of the day and you have a recipe for a major meltdown.

And so fear and anxiety form the underbelly of negative emotion for many sundowners. Individuals react differently to these basic



Continue on page 3



A Call to Action

Families—not institutions—provide the majority of care to chronically ill and disabled persons. These families know the enormity of the burden in caring for someone with Alzheimer's or Parkinson's diseases, stroke, traumatic brain injury, or other long-term conditions. They also know the challenges in locating appropriate advice, services, and respite.

Personal experience with community agencies, round-the-clock care, and financial hardships mean families know what the important issues are. This puts family caregivers in a unique position to act as advocates. Caregivers can educate elected officials charged with development of public policy and funding priorities.

This article offers tips for effective strategies for families to get involved in local, state, or federal advocacy efforts.

How Families Can Help Effect Change at the Public Policy Level

WRITE OR E-MAIL A LETTER TO YOUR ELECTED REPRESENTATIVE

Representatives rely on communication from their constituents to keep them informed and to know where constituents stand on critical or controversial issues.

A personal letter or e-mail is an effective method to get your message across. Due to security issues, email letters are sure to arrive before a letter through the US Postal Service. Write legibly, type, or e-mail your message and try to keep your communication to one (1) brief page. Make your message to the point. Example: "I'm writing in support of HR 1, the Long-Term Care Act." (Refer to the bill name and number, if you can.) Give a reason for your position (support or opposition). A personal experience is powerful in establishing your case. Let them know what you expect. Example: "I hope I can count on your support for this bill. Please write back and let me know your position on this important issue." Include your name and address on both the letter and the envelope or within your e-mail message.

Target and time your letter. Representatives will give the most weight to letters from their own constituents. However, if a bill is to be heard in a particular committee or subcommittee, you may need to communicate with the committee leadership (e.g., Chairperson of the Senate Health and Human Services Committee). In this case, explain that while you are not from the legislator's own district, you hope that the needs of all citizens will be considered in reaching a decision on the bill. Naturally, timing the letter before a vote is taken is critical.

Follow up by thanking your representative when his/her actions support your position. For addresses and where to write visit: <https://seniorresourceswmi.org/advocacy/contact-elected-officials/>

MAKE A PHONE CALL

When time is of the essence, a phone call can be a practical way to

express your concern to an elected representative. The most effective calls are to the Capitol offices, particularly when a vote is imminent.

Introduce yourself and provide your affiliation if you are working on behalf of a particular group, organization, or campaign. Be sure to mention if you are a constituent.

Do not expect to speak to your representative directly. Most likely, you will speak to a receptionist or legislative staff member. These individuals are responsible for keeping the legislator informed. Explain why you are calling. Example: "I'm calling to register my opposition to the proposed budget cuts for adult day care centers. Please be sure that Assembly member (name) is informed of my concern."

Where to phone: U.S. Capitol Switchboard in Washington, D.C., (202) 244-3121. The operator will refer you to any U.S. senator or U.S. representative (congressman/woman).

Faxing is also an effective way of sending your letter to a legislator. All state legislators and members of Congress have fax machines. Fax numbers can be obtained from the same sources as legislative and Congressional telephone numbers (see Where to phone above).

VISIT YOUR ELECTED REPRESENTATIVE

Meeting face-to-face with a legislator or designated staff member is an excellent way to establish a relationship and convey your point of view.

State legislators often go home to their district offices on Thursday or Friday. Meetings at the State Capitol are best set for Tuesday or Wednesday.

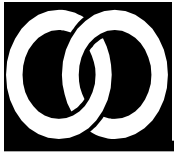
Congressional representatives in Washington, D.C. are more likely to come home on the weekend or on extended holidays or periods of Congressional recess. Contact the Capitol office to determine the best time to make an appointment.

Plan ahead. Legislators' schedules fill up weeks in advance. Plan your first visit before there's a "crisis" to establish friendly rapport.

Do not set your hopes on meeting with your representative in person. Legislators are busy and schedules often change at the last minute. An effective meeting can be held with a legislative staff aide (often the very people who craft legislation or brief their supervisors on important issues).

When you call the office, ask to speak to the scheduler. Introduce yourself, explain the nature of the visit, give the names and number of other people who will come along on the visit, how long you will need (for example, 15 to 30 minutes), and when you would like to visit. You may be asked to send a request in writing.

Do your homework by learning about the person you will visit. Rehearse what you will say, keeping in mind the legislator's background and interests. You may wish to begin by sharing your own personal caregiver story. Show your knowledge by mentioning any action taken or bills authored/supported by the



Continued from page 1

emotions. Some simply behave fearfully. But others react with anger, restlessness or crying. Some go into self protection mode and display violent behavior. Others act out tremendous confusion through wandering or pacing. These are the times it is important to remember that all behavior is a form of communication and the patient is not trying to cause problems but attempting to say something important.

Other triggers for sundowning (besides being carried off by well meaning relatives) would include:

- **A poorly lit environment.** Remember, the majority of sundowning incidents occur at sunset. People often keep only a few lights on to save electricity. But this exacerbates the fear of dementia patients.
- **A chaotic environment.** Perhaps you have teens coming home from school, playing their less than soothing music. Provide the patient with a quiet section of the house to escape the noise. Patients in nursing homes may become restless during the comings and goings of shift changes.
- **The day has been too busy and fatigue causing,** particularly late in the day.
- **The patient has too little stimulation and naps all day.**
- **The reduced light in winter results in a patient's version of Seasonal Affective Disorder.**
- **The patient has pain** that will not allow him/her to relax.
- **The patient is under stress.**

Although we don't understand the cause or have a cure for Alzheimer's Disease at this point, there are things we can do to lessen symptoms such as sundowners. In this take-a-pill society, we may wonder if there is a medication that can help. There is but there are significant risks. Sleeping pills are addictive and should not be taken for extended periods. The other class of drugs used for this purpose is antipsychotics. These are extremely strong drugs that are not licensed by the FDA for this purpose. Although they may help with sundowning, it is suspected they also increase the rate of patient mortality. Patients must be carefully watched while taking these drugs, including newer ones such as clozaril, risperidone, ziprasidone and several others. These medications will have different side effects with various patients and some trial and error might need to be involved. Melatonin is a safer alternative but should only be given with a doctor's permission. Whether your loved one is at home or in a facility, careful evaluation will need to take place balancing the side effects with the plus side. No one wants to see a patient suffer strong side effects just for the convenience of the caregiver.

Happily, there are a number of techniques to try with sundowners that have no adverse side effects. Of course, this is not a one size fits all proposition. A suggestion that works magic with one patient may be a total bust with another. But all

are worth a try!

- **Let there be light!** In the morning, open the curtains fully. Many patients have even profited from sitting in front of a full-spectrum light box commonly used by SAD (Seasonal Affective Disorder) patients. As evening draws near, close the curtains so the darkening skies are not noticed by the patient. Keep your loved one's area of the house well lighted and put in a night light for bedtime.
- **Examine medications.** Some of the patient's pills ~ unrelated to sundowners ~ may cause drowsiness that results in extra nap taking. These meds may no longer be necessary or can be taken at the end of the day when the sleepiness will serve a good purpose. The caregiver and doctor should review medications once a year for this purpose.
- **No napping!** Many patients become bored and nap all day. Then it is no wonder they are wakeful at night. Provide stimulation and activity to keep your loved one engaged during the day. Many caregivers send their loved ones to Alzheimer's Day programs that provide wonderful socialization and activity. If your patient is fatigued by nighttime, you can allow cat naps. Most experts advise us to keep these cat naps to 20 minutes at most.
- **Outside activities should be scheduled in the morning** whenever possible. Trips to the doctor, walking in the mall, visiting the beach, etc., may be too stimulating for later in the day. It is wise to schedule no more than two outside activities in one day.
- **Put your loved one on a healthy diet.** He may benefit from several smaller meals and snacks during the day. If a heavier meal is planned, it would be better at noon to allow adequate digestion time. Make stimulants like caffeine a thing of the past.
- **Establish a routine for your loved one.** Try to wake the patient, feed her breakfast, and structure the day in a routine, unthreatening way. This is particularly important at bedtime where bathing, brushing their teeth, going to the bathroom, etc., are all done at the same time and in the same order. This not only makes the patient feel safe, but also gives non-verbal cues that it will soon be time to sleep.
- **Use soft music to soothe the patient.**
- **Talk calmly and quietly to your loved one.** This may require a Herculean effort if it is late and you too are fatigued. But it is worth it not to make matters worse. If, despite all your efforts, your patient continues to be restless, try holding his hand or give him a hand massage.
- **Consider using something that will provide a cover noise** in the patient's bedroom. Therapists use a small machine that provides a subtle cover noise so no one in the outer office can hear the conversation. A looping tape playing the sound of waves can be utilized. Even the sound of a fan or bubbling aquarium can do wonders.

Continue on page 4

**The Mission Of Senior Resources
An Area Agency on Aging**

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 counties —
a mission compelling us to
target older persons in greatest
need but to advocate for all.

To contact us, please call

Amy or Mary at:

231-739-5858 or 800-442-0054

March's website: <https://www.dshs.wa.gov/sites/default/files/SESA/publications/documents/22-277.pdf>

Continued from page 3

- **If your patient is a wanderer, you may need locked doors and motion sensors.** If the equipment has an alarm, make sure it is kept near you, not the patient as it will frighten her and make matters worse.

Caregivers for dementia patients with sundowners are heroes of our society. We sincerely hope this article may have hit upon a solution that may make your life easier.

By Andrea Heeres



Continued from page 2

legislator in a similar area, if appropriate.

Be clear about the purpose of the meeting. Example: "I am here today to help familiarize you with the needs of family caregivers," or "I would like to know if I can count on your support for improving the quality of care in nursing homes."

Add your voice to others who share similar concerns by joining a larger group or organization going to visit the Capitol. This way you can coordinate with existing efforts and increase your clout.

Understand that current fiscal constraints make it difficult to advocate for increased funding for programs and services. Do not apologize for this fact. Instead, be clear about the importance of a program or service to you and your family. Example: "I know funding is tight and not everything can be considered a priority, but I am here to tell you what is a critical issue for me and others like me."

Bring a few brief written materials, if available, to leave in the office which relate to the purpose of your visit. Remember to thank the legislator or staff for your meeting. It is also a good idea to send a thank you letter or email message addressed to the legislator.

