

When and How to Say “No” to Caregiving

by Deborah Colgan, MA, M.Ed., NCC

*W*hen is it time to say “No”?

How does a caregiver know when he or she can no longer manage the daily caregiving routines and planning responsibilities? What signals alert the caregiver that he or she is in trouble of getting lost in caregiving? Can a caregiver who cherishes a loved one set limits on responsibilities without feeling guilty or morally bankrupt? These are questions at the heart of successful, long-term caregiving. Unfortunately, for most caregivers, these questions do not arise until they are feeling overwhelmed and depleted.

Being able to say, “No, I can no longer continue to provide care in this way,” may not only save the caregiver from emotional and physical burnout but can also open up opportunities of shared caregiving responsibilities with others while deepening the level of honesty and openness in the relationship.

Saying “No” may seem like a harsh statement to a caregiver who prides herself on being a helpful, kind, and loving person. In fact, most caregivers choose to become one because they feel a moral imperative to do so. This imperative may come from several sources including family relationships and roles, friendship ties, and social expectations.

Families often select the primary caregiver from cultural norms such as the youngest unmarried daughter or the oldest son as being responsible for a parent’s care. Friendship ties provide many single elders with caregivers who act in lieu of local family members. In the U.S., the social norm is for family and friends to provide care to elders first before the government.

Current statistics show that most of the elder care is provided by families and other members of an elder’s informal social network. Proximity is also a component. The closer one is geographically, the more likely he or she will become the caregiver. Personal values derived from one’s faith or spiritual practices may lead a person to feel called to provide care.

Moral decision making based on values such as, “Everyone has the right to stay at home if they choose no matter what,” may encourage a person to become a caregiver.

Wherever the imperative is coming from, the role of the caregiver is intimately linked to that person’s code of ethics and the way in which the person chooses to act in his or her own life.

What does say “No” mean anyway?

Is it a final giving up of duties that implies the caregiver is ending the relationship and leaving a loved one to fend for himself? Maybe the “No” means, “I’m tired and feel trapped.” Maybe the “No” means, “I have failed to be all I could be as a caregiver.” Maybe the “No” means, “I can’t do what you want me to do, and I feel inadequate.” Or maybe the “No” just means, “I am so tired, I have to stop.” The word “No” can have different meanings for different people. “No” doesn’t necessarily have to have a negative connotation attached. “No” can be understood as a pause, a time for reflection, a breathing period or, “Let’s stop and talk this over. Things need to change.” Exploring the meaning of “No” for the caregiver is often the first step in establishing better emotional boundaries.

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.



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Healthy emotional boundaries are important in helping the caregiver distinguish between his or her own needs and the needs of the care recipient. Boundaries remind the caregiver and elder that their relationship is between two adults and that there need to be expectations of mutual respect and autonomy for the relationship to be successful.

The ideal time to discuss caregiving boundaries is in the beginning when both people are new to the process of developing this special relationship. Talking about needs in a calm and supportive way allows each member to feel the other's concern while acknowledging that the relationship will have some limitations.

In an idealized world of caregiving, the care recipient could turn all problems over to the caregiver without any worries or stress and the caregiver would have limitless capacity for love and work. But neither of these situations is realistic. Getting off to a good start by talking about boundaries as part of a healthy relationship lays the groundwork for developing emotional resilience and flexibility to respond to an increase in the elder's care needs, while managing the inevitable caregiver stress.

In practice, most caregivers address the issue of their own limits after the caregiving relationship gains full steam. Caregivers often get inducted into helping through a sudden major health crisis of a loved one or by the slow but steady process of taking on tasks and responsibilities for the elder as she experiences aging and the loss of function.

In the first instance, addressing the immediate and critical health care needs of the elder takes precedence over long-term care planning. However, as soon as the elder is stable, the time is right for the caregiver to discuss boundaries and limits.

In the second instance, caregivers need to raise the issue of boundaries as soon as they begin to detect the first signs of their own stress or burnout. Signs such as avoiding the loved one, anger, fatigue, depression, impaired sleep, poor health, irritability or that terrible sense that there is "no light at the end of the tunnel" are warnings that the caregiver needs time off and support with caregiving responsibilities.

Setting emotional limits involves a process of change with five key steps.

First, the caregiver must admit that the situation needs to change in order to sustain a meaningful relationship. Without change, the caregiver risks poor health, depression, or premature death. The primary caregiver is such an important person to the elder that impaired caregiver health puts the elder at further health risk.

Second, the caregiver must reconsider personal beliefs regarding what it means to be a good caregiver. Since the caregiver generally has moral expectations of his or her own behavior, redefining what "should" be done to what is reasonable and possible to do can be a liberating moment. This may include lowering some expectations of one's ability to do things and delegating tasks to others.

Third, the caregiver needs to identify key people (friends, family, or professionals) who can support and guide the caregiver through this change process. Frequently, caregivers join support groups with other caregivers to reinforce their commitment to change or hire a geriatric care manager coach. A support group is also a place to express anger, anxiety, frustration, and sadness about the caregiving experience

instead of inadvertently having these feelings pop out during a tense conversation with a loved one.

Fourth, the caregiver needs to develop communication tools to express the need for boundaries. Honesty and simplicity in talking about feelings and needs does not come easily, particularly if one is not familiar with having these types of direct discussions.

Lastly, the caregiver must be able to sustain this new approach while allowing the elder time to react and express his or her feelings about the changes. Readjusting the balance in any relationship takes time, especially when both members have competing needs.

There is a simple but effective communication approach that can help caregivers express feelings and set boundaries.

This approach encourages the caregiver to speak from an “I” point of view, in a non-accusatory fashion, expressing the caregiver’s limitations or feelings and offering an alternate solution. Some examples of “I” statements are:

- *“I can no longer drive you to all of your medical appointments due to my work schedule and my limited time off. I know this will be a change for you. I suggest we look into other transportation options such as the Busy Bee Medical Transport Service.”*
- *“Mother, I am unable to continue with the responsibility of cleaning the house weekly. I want to spend my time with you on other matters. I know it’s hard to let newcomers help, but I think it is time to hire a homemaker service you would be comfortable with.”*

In each of the above statements, there is a presentation of what the speaker cannot continue to do, an acknowledgment that the change will have a consequence for the elder and a suggested solution. No attempt is made to make the elder feel guilty about the effort the caregiver is expending or the caregiver’s stress level.

Setting the boundary is the caregiver’s responsibility. At first, expressing boundaries in “I” statements may feel awkward, but with practice, caregivers can learn to raise difficult topics by establishing a comfortable atmosphere for discussion.

Initially, the caregiver may experience resistance on the part of his or her loved one to dialogue about changes as to the provision of care. Gentle persistence is needed to attend to the need for new boundaries. Discussions that can be introduced at a time when both individuals have lower stress and are feeling quiet and comfortable with each other are discussions that have a greater chance of success.

Avoid making decisions about change during emergencies. Waiting until the situation is calm and both parties can take time to think through issues creates an atmosphere of joint decision making and ownership of the outcome. Making changes in small steps toward a larger change gives everyone a chance to adapt comfortably.

Caregiving is a dynamic relationship that evolves over time. As caregiving tasks increase, so will stress on the caregiver. A caregiver and his or her loved one will manage this challenge successfully if each person is able to express directly what he or she needs, wants, or can do. ❖



This month we celebrate our caregivers who are loving and supportive husbands, sons, and fathers. If you are the friend or relative of a male caregiver trying to do it all, please, as much as possible, give the gift of help.

June’s Website

www.dailycaring.com

Quotes

Prioritize your goals, and then truly enjoy the most important things.

“If you obey all the rules, you miss all the fun.”

Katharine Hepburn

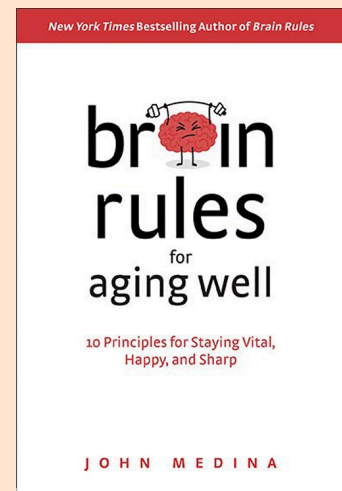
So true that a lot of stress comes from not finishing things we have started.

This Month’s Book

Brain Rules for Aging Well

by Dr. John Medina

This groundbreaking new book reveals scientific insights into the aging brain—and the prescription for aging well—in his engaging signature style.



Respite Care: Need It Once in A While!

by Helen Hunter, ACSW, LSW

Respite is a period of rest or relief. For those who give constant care, whether it is for an aging parent, an ill relative or for babies or small children, respite care can be very welcome indeed. The need to relieve a primary caregiver is becoming more apparent, and community agencies are training personnel who serve as respite workers for those in need.

Respite workers go through many hours of instruction to understand the needs of both the caregiver and the care receiver. Their primary purpose is to relieve the primary caregiver. They provide companionship and supervision. They can also provide comfort and safety by providing meals and snacks, taking walks around the neighborhood, engaging the person in stimulating activities such as reading, listening to music, making a craft, or completing a crossword puzzle. Respite workers are *NOT* allowed to administer medications or provide housekeeping or chore services.

While most respite work is found in the home, this service may also be performed in other arenas. Some caregivers take their family members to a day facility, where meals are provided and participants can engage in a variety of activities, such as exercise classes, crafts, reading discussion groups and writing classes. Other caregivers may need occasional help from an assisted living facility or a skilled nursing facility. Some facilities will provide respite care for a few days, and some can take care of a person for up to a few weeks.

Respite care is available for family members who try to “do it all” when it comes to caring for their loved one but need a break occasionally. It is very important! ❖

Hyperthermia: Too Hot for Your Health

During the summer, it is important for everyone, especially older adults, and people with chronic medical conditions, to be aware of the dangers of hyperthermia. Hyperthermia is an abnormally high body temperature caused by a failure of the heat-regulating mechanisms in the body to deal with the heat coming from the environment. Heat stroke, heat syncope (sudden dizziness



after prolonged exposure to the heat), heat cramps, heat exhaustion and heat fatigue are common forms of hyperthermia. People can be at increased risk for these conditions, depending on the combination of outside temperature, their general health and individual lifestyle.

Older people, particularly those with chronic medical conditions, should stay indoors, preferably with air conditioning or at least a fan and air circulation, on hot and humid days, especially when an air pollution alert is in effect. Living in housing without air conditioning, not drinking enough fluids, not understanding how to respond to the weather conditions, lack of mobility and access to transportation, overdressing, and visiting overcrowded places are all lifestyle factors that can increase the risk for hyperthermia.

People without air conditioners should go to places that do have air conditioning, such as senior centers, shopping malls, movie theaters, and libraries. Cooling centers, which may be set up by local public health agencies, religious groups, and social service organizations in many communities, are another option.

The risk for hyperthermia may increase from:

- Age-related changes to the skin such as poor blood circulation and inefficient sweat glands
- Alcohol use
- Being substantially overweight or underweight
- Dehydration

- Heart, lung, and kidney diseases, as well as any illness that causes general weakness or fever
- High blood pressure or other health conditions that require changes in diet. For example, people on salt-restricted diets may be at increased risk. However, salt pills should not be used without first consulting a physician.
- Reduced perspiration, caused by medications such as diuretics, sedatives, tranquilizers, and certain heart and blood pressure drugs
- Use of multiple medications. It is important, however, to continue to take prescribed medication and discuss possible problems with a physician.

Heat stroke is a life-threatening form of hyperthermia. It occurs when the body is overwhelmed by heat and is unable to control its temperature. Heat stroke occurs when someone's body temperature increases significantly (above 104 degrees Fahrenheit) and shows symptoms of the following: strong rapid pulse, lack of sweating, dry flushed skin, mental status changes (like combativeness or confusion), staggering, faintness, or coma. Seek immediate emergency medical attention for a person with any of these symptoms, especially an older adult.

If you suspect someone is suffering from a heat-related illness:

- Get the person out of the heat and into a shady, air-conditioned, or other cool place. Urge the person to lie down.
- If you suspect heat stroke, call 911.
- Apply a cold, wet cloth to the wrists, neck, armpits and/or groin. These are places where blood passes close to the surface of the skin, and the cold cloths can help cool the blood.
- Help the individual to bathe or sponge off with cool water.
- If the person can swallow safely, offer fluids such as water or fruit and vegetable juices, but avoid alcohol and caffeine. ❖



Be Sweet to Your Feet

Your feet work hard to get you where you need to be. But years of wear and tear can be rough on them. So can disease, bad circulation, poorly trimmed toenails, and wearing shoes that don't fit.

So be kind to your feet. Exercise, especially walking, is a great way to increase blood flow, which helps your feet stay healthy. Try simple foot exercises, such as sitting and rotating your ankles one way, then the other.



Foot problems are sometimes the first sign of more serious medical conditions such as arthritis, diabetes, and nerve or circulatory disorders. Check your feet often, looking for cuts, blisters, or ingrown toenails. Talk with a doctor if you notice numbness or severe pain in your feet.

Tips for Happy Feet

- Wash your feet regularly, especially between your toes.
- Wear clean socks.
- Wear well-fitting, comfy shoes.
- Wear shoes when you're outside.
- Put your feet up when you're sitting, to help circulation.
- If you're sitting for a long time, stand up and move around every now and then.
- If you cross your legs when sitting, reverse or uncross them often. ❖

Hearing

Tips to improve communication with a loved one who may be hard of hearing:

- **Reduce background noise.** Competing noise from the television or radio can make it more difficult to hear.
- **Take turns while talking.** It can be challenging to follow the conversation when multiple people are speaking at once. Encourage everyone to adopt this practice.
- **Speak clearly, but don't shout.** Louder isn't necessarily clearer—and nobody likes to be yelled at when they're trying to enjoy themselves.
- **Face your loved one directly as you speak.** Don't turn your back on your conversation partner or shout from another room. People often need to see your lips and facial expressions to understand what you're saying.
- **Use good lighting.** A dim room will limit the visual cues (e.g., mouth movements) that people with hearing difficulties often use to help them decipher what someone is saying.
- **Be patient.** Try not to get annoyed if you must repeat your message. If someone doesn't understand you the first time, rephrase what you said. Don't give up on communicating!
- **Seat guests strategically.** Arrange the dinner table with conversation in mind. Seat the person with hearing difficulty next to someone who will help keep them involved.
- **Learn the signs of hearing loss.** These include raising the TV volume beyond what's comfortable for others, frequently requiring speech to be repeated, and seeming irritable or withdrawn.
- **Encourage your loved one to seek help.** A person might not think their hearing is that bad. But many people underestimate their level of hearing trouble. Be gentle but persistent. Let them know you're concerned, that treatment can improve their lives immensely, and that you can help them. ❖

What Did You Say?

by Jennifer Buckley

Do you find the need to repeat yourself often to the person you are caring for? Does your talking level closely resemble your yelling level just so your loved one can hear you? Are you speaking so slowly that you end up losing your train of thought?

It is possible that the person you are caring for is one of the 28 million Americans experiencing hearing loss. Unlike incontinence, hearing loss is a natural sign of aging due to a change in the structure of the ear. After age 65, one out of three Americans at least partially loses their hearing. However, it is not only a result of the aging process. There are other causes of hearing loss that include:

- Build-up of earwax
- Chronic middle or inner ear infections
- Medical conditions like diabetes or a brain tumor
- High blood pressure
- Exposure to excessive noise like heavy machinery
- A blood clot in the nerves of the ear
- Tinnitus- (a common syndrome indicated by a ringing sensation in the ear)
- Meniere's Disease - (excess fluid in canals of the inner ear)

Before deciding upon the kind of treatment the person you are caring for should receive; their doctor should determine the cause of their hearing loss. But, as a caregiver, you can provide some helpful hearing care hints to your loved one to help them communicate more easily.

- Look at people when they are talking to you
- Begin relying on your sense of sight by installing a flashing bulb on doorbells, telephones, and fire alarms.
- Limit background noise during conversations



- Sit in the front row during church, school or in an auditorium
- Look into buying an assisted hearing dog that responds to certain noises
- Check out hearing aids. You can buy one on a 30- day trial period
- Ask about assisted hearing devices before you buy a television

Helping your loved one to hear better will not only benefit them, but it will also benefit you greatly.



Signs of Hearing Loss

Many loved ones will not tell their caregiver of an onset of hearing loss, for fear of losing independence. Instead, they become isolated, depressed, angry, lonely, frustrated and even physically ill. Some telltale signs are when a loved one withdraws from their normal social activities, refuses to attend family and friend gatherings, or does not answer the phone anymore, saying they were busy or unavailable. Any avoidance of conversation is cause for concern.

A loved one may:

- have trouble distinguishing between words that sound alike
- offer responses to questions that do not make sense, have a hard time understanding women and children
- turn head to one side, or cup an ear to hear better
- respond often with a smile and nod, but no further comments
- have difficulty with conversation while riding in a vehicle
- withdraw from group discussions and gatherings
- not hear the phone or doorbell, and
- have the volume on a TV or radio set extremely loud.

Some physical symptoms that may occur with hearing loss include a ringing, roaring, hissing or buzzing in the ear, also known as tinnitus; ear pain, itching or irritation; fluid or pus leaking from the ear; and vertigo. Caregivers can keep a watchful eye on their loved one for these behaviors and physical symptoms. ❖

INVITATION TO TAKE PART IN THE

SWEL Care Study 

Who can take part?

Individuals who are Black or White living with and helping a family member or friend who has Alzheimer's or related dementia. Participants must be residents of the state of Michigan.

What is involved?

Family Member/Friend

- Baseline Interview by phone (1.5 to 2 hours)
- Training Session by phone or Zoom (1.5 to 2 hours)
- Daily Life Assessment: wear two heart monitors and complete

Person living with dementia:

- Complete a Memory Screener (10-12 minutes)
- Attend at Training Session by phone or Zoom (20 minutes)
- Wear one heart monitor on the chest for 5 days

Other Information

- Participation is voluntary and takes place in your home during daily life
- Information you provide will be kept private
- The family member/friend and the person living with dementia can receive a combined amount of up to \$400 for taking part in this study.

NEED MORE INFORMATION or INTERESTED IN PARTICIPATING?

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