

When and How To Say "No" to Care giving

By Deborah Colgan

When is it time to say "No"?

How does a caregiver know when he or she can no longer manage the daily care giving routines and planning responsibilities? What signals alert the caregiver that he or she is in trouble of getting lost in care giving? 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 care giving. 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 care giving 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 a number of 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 United States, the social norm is for family and friends to provide care to elders first before the government. Current statistics show that the majority of elder care is provided by families and other members of an elder's informal social network. Proximity is also a component in care giving. The closer one is geographically to a loved one, 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 humanistic 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 saying "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 to its meaning. "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.

Healthy emotional boundaries are important in helping the caregiver distinguish between his or her own needs and the needs of the person being cared for. 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 care giving 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 care giving, 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 care giving relationship gains full steam. Caregivers often get inducted into helping through a sudden major health crisis of a loved one (such as a heart attack) 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 either situation, the caregiver and care recipient aren't necessarily thinking about being in a relationship but about getting the jobs done that need to get done. 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 care giving 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 care giving 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.”

- “Dad, I can no longer assist you down the outside stairs. I am worried about your safety and mine. I believe we need to build a ramp for easier access to your home. I have found a carpenter who has reasonable rates for construction.”

In each of the above statements, there is a presentation of what the speaker cannot continue to do, an acknowledgement 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. It is understood the elder knows the caregiver is working hard. Setting the boundary is the caregiver’s responsibility. There is, however, an invitation for discussion and joint problem solving. 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.

Care giving is a dynamic relationship that evolves over time. As care giving 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. A relationship that allows for and respects boundaries and individual limitations can expand to include other caregivers without the risk of lessening the importance of the primary relationship that sustains the elder in the aging process.

Deborah Colgan, MA, M.Ed., NCC, therapist and educator, currently serves as the Director of Community Development for South Shore Elder Services, Inc., a private non-profit organization that is the Area Agency on Aging and Aging Service Access Point for eleven cities and towns in southeastern Massachusetts. Ms. Colgan has provided clinical and support services to families for the past thirty years

This article was taken from the Fearless Caregiver Newsletter, April 12, 2011, Issue #29. Sign up for the Caregiver.com weekly e-newsletter by going to www.caregiver.com. Click on Newsletter, and then click on Subscribe to Newsletter.