

Ask the Expert

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What should families understand about the guilt that often accompanies caregiving?

Guilt is a common experience of family caregivers. Often it is triggered by what family caregivers believe they should do, do more of or do better. Or what they have failed to do under circumstances they may have never before faced. It is not so much a feeling about actual wrongs that have been committed but expectations that are mismatched with the increasing demands of taking care of another person. Wrongs are more likely to be perceived rather than actual. Caring for someone we have known and loved who may not be aware of the needs we see, or agree with what we believe needs to be done, is new territory. In one sense, caregivers recognize that a disease like Alzheimer's changes the way someone they have known perceives and responds to situations. In another sense, they realize they must act in the best interest of the person receiving care - even if he or she does not agree with what is best or right. However, this acknowledgement does not diminish the burden family caregivers describe as guilt.

Caregiver guilt is an issue of considerable importance to family caregivers and professionals helping them. Persistently perceived guilt is a threat to a

caregiver's well-being and healthy complete sense of self. Excessive guilt increases caregiver stress, encourages depression and complicates processes of grief and mourning. We need to understand the sources of caregiver guilt and how to effectively manage guilt when it becomes a negative force.

First, caregivers must recognize that what they are feeling is guilt. A healthy sense of guilt directs us to act in ways that are consistent with what we believe and value, to change what can be changed. An unhealthy sense of guilt distorts our perspective and drives us to feel responsible for everything that does not work out like we think it should. Caregivers become vulnerable to this when they do not understand what they can reasonably expect to happen in dementia caregiving. Many times caregivers feel guilt about something that has no rational basis. This is why it is so important to learn about Alzheimer's disease and how it affects the thinking and behavior of those we love.

Our expectations of ourselves and others contribute to feelings we experience as guilt. Our view of what needs to be done is distorted: we cannot do enough, nor do it well enough to feel comfortable. We may label this unpleasant feeling guilt. We may react to this feeling by doing more tasks, thinking that by doing more we will feel less guilty. This kind of

response leads to a compulsive performance of tasks which might explain why some caregivers become so overwhelmed with tasks.

Overstressed and socially isolated caregivers may become more vulnerable to feelings of guilt. In their social and psychological isolation, they lose the feedback they had previously received from friends and other family members, which serve as a rudder to keep them on course with their values and beliefs. Without "feedback rudders," we become trapped in the world we see alone. As dementia worsens, our loved ones are no longer the consistent and reliable sources of feedback we may have once depended on. Caregivers need to find others to serve as "feedback rudders."

Guilt may have other meaning for caregivers. Some of the most powerful guilt-provoking situations also represent major transitions in what has become a journey of shared losses. The same situation for the caregiver and the person being cared for may trigger different losses of equal importance. One example of this is taking away the keys from the person who argues he has driven safely since the age of eleven. For the person who will no longer drive the loss may be perceived as never being able to go where he wants when he wants. For his spouse the loss is not being able to go places together as in the past. She might also sense a loss of the partnership she and her husband had developed to deal with challenges confronting them both. When confronted by these situations, we eventually

realize that the same events that initially trigger feelings of guilt, will a few moments later lead us toward a broader awareness of loss: theirs and ours. Guilt may be our initial response to some of these examples, but sometimes we may be misreading what we are feeling. If we will look beyond feelings of guilt we may be able to identify other feelings associated with loss.

Guilt feelings are also associated with grief and loss. Grief is a constant companion to family caregivers. One good example of this process is the decision to place a loved one in another care situation such as nursing home. The spouse of the person with dementia recognizes the growing need to make decisions. His or her health has been declining. The needs of the loved one with dementia are quickly exceeding the caregiver's capacity to provide appropriate care. Yet whenever the person starts to take the steps to act on this need, a terribly unpleasant feeling emerges, one that is often labeled guilt. Even though the change might improve the care of the person with dementia and health status of the family caregiver, guilty feelings cause barriers to placement. So what is the basis for guilt here? Nothing wrong has yet occurred.

Whenever a significant change is about to occur, a caregiver's awareness is focused on what has been happening to the person they have been caring for and what they have been able to do. They are faced with a growing awareness of how this has changed them. The fact that they realize they

can no longer provide this care is not a statement of their failure but the dominance of a disease like Alzheimer's. It is a fact of their human existence. They are facing what they cannot stop: the loss of their loved one and the life they have shared. That is what has triggered feelings of guilt.

Caregivers are experiencing feelings that represent the confrontation with and acknowledgement of pain and loss, causing uncomfortable feelings. Previously, they have been able to keep this awareness in the background until some kind of separation is necessitated by more care than they can provide. Understanding that these feelings are not marks of guilt but the anticipation of loss is important. Instead of dealing with misleading feelings of guilt, they can move to a psychological and spiritual place within themselves, and their family, that allows them to resolve what is and is not possible, and then be prepared to anticipate future days of healing as they develop a new life for themselves from which loved ones are missing.