

## When Your Loved One Isn't Very Loveable

Soon after Virginia Hoffman's husband was diagnosed with Lou Gehrig's disease he began a spiraling descent into anger. During the five years she cared for him until his death, he never let go of that anger. He also wanted her with him all the time and lashed out at her because he was angry.

**The root of the problem.** There are many reasons why a loved one needing care may be classified as 'difficult'. It may be the disease, as is the case with Alzheimer's, which can turn kind, gentle, cautious people into swearing, violent and paranoid strangers. It can be the prognosis, leading the care recipient to feelings of anger, resentment, guilt, depression or frustration, which they unwittingly take out on the caregiver.

Or it can be personality, which loss of control magnifies. So your overbearing, stubborn or independent mother becomes more so under your care, or your uncommunicative husband becomes snappish and sarcastic at your every comment. For many, the loss of self-determination and the loss of freedom are the root of the difficulties. Dr. Vincent Figueroa, assistant director of the Medical Illness Counseling Centre in Chevy Chase, Maryland, says that most of the problems stem from the fact that we forget the person's developmental needs. We know what the medical needs are and we try to oversee those carefully, but as the person loses autonomy, they begin to act out.

**Understanding why.** Learning the cause of the difficult behavior is the first step in figuring out how to deal with it. Depression is a common side effect of long-term illness or disease and if left untreated, can manifest in an array of difficult behaviors. Given proper medications, they unwanted behaviors often disappear.

If a new medical problem is not the cause, simply knowing what is normal for a particular condition may bring the caregiver some understanding. A woman whose husband has dementia said that it helped to know that his behaviors were normal for someone with Alzheimer's. She felt better knowing that his happens to most people with the disease.

Prior problems between the caregiver and the person needing care can compound the caregiving effort and be the cause of a difficult, or even unbearable, situation. For example, a couple who never communicated feelings while both partners were well may be unable to discuss how the illness is affecting them. Instead, both may act out their anger, sadness, and frustration on the other, thereby compounding the original problem. Gaining an intellectual understanding of why your loved one is being difficult is an important thing to do, but it doesn't make living with them any easier.

**Acknowledge your feelings.** It is okay to feel frustrated and angry. Perhaps you are feeling guilty that it is not you who is ill. You might feel just as angry as your loved one, because even though you do not have the illness, your life has been profoundly affected as well. In some cases, it may be your anger or fears making the caregiving effort more difficult. You may need to step back and think about your own emotions.

As a caregiver, you are walking a fine line between caring for yourself, providing needed care and trying to influence or make decisions on behalf of your loved one; all of which can cause friction. Wherever possible, allow your loved one to make decisions, however small, as our need for control does not go away.

At the same time, it is important to retain your own control, for example, by setting limits on the number of times per hour that your loved one demands your attention.

Arrange for help. Accepting help is healthy. Even in the best and most loving situations, caregivers need a break. When the recipient is difficult, respite becomes essential for the caregiver's health. There are indicators that you may need help, such as if your family member is not eating or is very aggressive, or if you are angry, not eating or irritable. There are a range of options from in-home respite, adult day away programs and short stay beds to placement in long term care home. Help from others comes in many forms, such as grocery shopping, sharing a cup of tea or offering a ride.

Support groups are touted as one of the best ways to deal with a difficult situation, simply because they provide an outlet for the caregiver's frustrations, questions, fears and guilt. Support groups offer problem solving and emotional support in a confidential and supportive environment.