

When Your Loved One Isn't Very Loveable by Marla Gold

Soon after Virginia Hoffman's husband was diagnosed with Lou Gehrig's disease she began a spiraling descent into anger. During the five years she cared for him until his death in 1990, he never let go of that anger. "He wanted me with him all the time, and he lashed out at me because he was angry," she recalls. "When I was caring for him, I felt like I was the only one in the world who was going through something like this. It was very difficult," she remembers.

The family of Gene Cannon also understands the frustration of caring for a difficult care recipient. His wife, Edie, and their seven grown children cannot rely on friends to help care for the 79-year-old Alzheimer's sufferer, because he is too violent and distrustful to allow even his closest friends near. In fact, his family had to hide the kitchen knives to ensure that he cannot carry out his threats to kill them.

For the parents of 14-year-old Valerie Smith, caring is a constant battle between the teenager's need for autonomy and her parents' fears about their HIV-positive child. While all caregivers face adversity, families caring for family members who, due to personality, temperament, or disease, are angry, violent, or uncooperative face an almost impossible task. Is it even possible to provide loving, quality care to a person who tries to hit, refuses medication or food, tells you he hates you, or acts as if you aren't even there? Yes, say the experts, but it takes a lot of patience and practice, as well as recognition of your own frustration and anger.

The root of the problem

There are myriad reasons why a care recipient may be classified as "difficult," says Dr. Vicente Figueroa, assistant director of the Medical Illness Counseling Center in Chevy Chase, Md. 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. Says Dr. Figueroa, "Most of the problems I see 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." Figueroa has seen children refuse to take medications or eat right in their efforts to maintain control.

"I've seen kids with cancer who have run away," Adds Katie McGuire, program service coordinator with the Muscular Dystrophy Association, "With ALS (Lou Gehrig's disease) and many other illnesses, you are losing control of everything. So you need to control what you can--which often is the caregiver." Understanding that made a huge difference for Virginia Hoffman. "My husband lost control of his life and began to control mine. He wanted me with him all the time, and refused to allow others--even our son--to help care for him."

Understanding Why

Learning the cause of the difficult behavior is the first step in figuring out how to deal with it, says Dr. Peter Rabins, professor of psychiatry at Johns Hopkins University School of Medicine, and the author, with Nancy Mace, of "The 36-Hour Day," considered by many to be the bible for the Alzheimer's disease caregiver. Rabins says the first stop should be to the family physician to make sure the correct diagnosis has been made. In one case I know of, an elderly woman became very agitated seemingly for no reason. She had fallen and broken her hip, but because she could not remember the fall or locate the source of pain, she acted out. A visit to the doctor located the break, and she regained her calm demeanor.

Depression also is a common side effect of long-term illness or disease, and left untreated, can manifest in an array of difficult behaviors, says Dr. Nathan Billig, professor of psychiatry at Georgetown University Medical Center, and the director of the University's Geriatric Psychiatry program. Given proper medications, the unwanted behaviors often disappear.

If a new medical problem is not the cause, simply knowing what is normal for a particular condition may help, says Edie Cannon, who has been a caregiver since February 1994. "It helps a lot to know that his behaviors are normal for someone with Alzheimer's. It makes you feel better to know that this happens to most people with the disease," she says.

Prior problems between the caregiver and care recipient 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. The same may be true for a couple whose long awaited child is born with a birth defect or a debilitating illness.

Gaining an intellectual understanding of why your care recipient is being difficult is an important thing to do, but it doesn't make living with them any easier. Hopefully, the following suggestions will help:

Acknowledge your feelings

Virginia Hoffman, the former caregiver, suggests acknowledging your feelings of frustration or anger is a necessary thing to do. "Know that it is okay to feel the way you feel," she says. "Don't feel guilty that it is not you who is ill, and realize that it is okay to feel as angry as the care recipient is, 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 need to try and step back a bit and come to terms with your own emotions.

Sometimes, it is necessary to vocalize your feelings to your partner, says Hoffman. "Tell the person that this is difficult for everyone. Say, 'Just as I am trying to understand what you are going through, try to understand what I am going through with you.'"

When simply expressing your feelings is not enough, McGuire suggests removing yourself--temporarily--from the situation. "I've had people tell me that when their frustration level got really high, they pulled harder than necessary on their loved one during transferring. Recognize when you are becoming destructive to yourself or your loved one, and get out of the situation. Come back once you've cooled down."

Separate the person from the disease

Reminisce and remember the good times, say the experts. "One woman I work with watches videos to remind herself of why she's still around caring for an increasingly

surly and uncooperative spouse," says McGuire. Joyce Cannon says memories are what propels her family forward as well. "We always idolized dad, and we still do. We know it's not his fault he acts this way. We remember that he was always there for us, and I'm sure we drove him crazy at times."

Says McGuire, "When things are bad, remind yourself that this person is sick and the behavior is not directed at you." Adds Hoffman, "As angry as my husband got, I never lost sight that he had received a death sentence and had lost everything." Hoffman, who facilitates a Lou Gehrig's support group through the MDA, tells caregivers who are reaching the end of their rope to put themselves in the care recipient's shoes. "You know what they are going through, so when you get angry or frustrated, think about what the other person is losing."

In many cases, the illness brings up unresolved familial issues, such as an overbearing mother or an unforgiving father. Even though it is a difficult thing to do, it is important that caregivers try not to allow family history and dynamics to interfere with their caregiving, says Billig. "You must remove yourself from the history with this person," he says. "Focus on the care needs (making the house accessible, finding a home care aid, etc.) not on the personality. And keep your focus in the short-term."

Arrange for help--quickly

When Jane Blatt, a cancer recovery patient herself, learned that her husband, Bob was diagnosed with ALS she thought they should be inseparable, "We don't have a lot of time, so let's make every second count." Blatt found out the hard way that she should have gotten into the "help mode" right away. Once Bob became very ill, he resisted outside help--it took Jane more than six years to convince him that she could not take care of him alone. Her own degraded health and the intervention of family members finally swayed him.

"Caring for someone is more than a full-time job, so arranging for help is healthy," confirms Dr. Rabins. "It is not running away." The fact is, even in the best and most loving situations, caregivers need a break. When the recipient is difficult, respite becomes essential to the caregiver. In some cases, a loved one may become too difficult to be cared for by one person at home. There are signs that a caregiving change may be necessary, says Rabins. "If the care recipient is not eating or is very aggressive, or if you are angry, not eating, irritable...that's an indicator that you may

need outside help." Rabins mentions a range of options, from day programs to help at night to placement in an institutional setting.

In fact, experts stress the need for caregivers to indulge themselves occasionally, so that they stay healthy. "Know that you need respite, exercise, and socializing to avoid becoming ill also," says Dr. Billig, author of "Growing Older and Wiser: Coping with Expectations, Challenges, and Change in the Later Years." "Evidence has shown that the incidence of illness among caregivers is extraordinary. So figure out how others can help--tangibly and emotionally--and let them," he says.

When the care recipient is difficult, finding respite caregivers and other helpers is easier said than done. "People don't want to be around sickness, and when a person is difficult, they definitely don't want to be around," says McGuire. To get around this problem, your circle of helpers needs to be larger, and may need to include paid as well as unpaid respite caregivers. Jane Blatt found that by warning others of her husband's moodiness and explaining that he was so difficult because he was in pain and losing control of his body, family and friends were more willing to help. "Once they understood that this was not his true personality--grumpy, snappish, and ungrateful--they offered to help more," she says.

McGuire suggests recruiting volunteers from religious groups, civic associations, and other forums to provide backup help. And remember that help comes in many forms, such as grocery shopping, cooking, and cleaning.

Outside support

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 frustration, questions, fears, and guilt. Says Dr. Rabins, "There is good scientific evidence that caregivers who go to support groups have a better ability to deal with the illness." Adds Blatt, "They let you know you're not alone." Support groups offer problem solving and mental support to others in similar situations.

Hotlines are another resource. The Cannon family is in constant touch with the local Alzheimer's Association chapter hotline. "Every time we face something new, we call. I do not think we would have gotten this far without support from them," says Mrs. Cannon.

In many situations, personal or family therapy helps to overcome seemingly insurmountable problems with difficult family members. "It often helps to have a third party to help negotiate out problems," says Dr. Figueroa.

Retain Your Loved One's Autonomy, Help Them Develop Their Independence
"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," says Dr. Billig. "This is often the cause of a great deal of friction." One way to alleviate this problem is by striving constantly to allow your loved one to make her own decisions--even if they are small. While your wife cannot direct the course of her illness, perhaps she can choose between two qualified doctors, or your 10 year old can select from among two meal choices. The need to have some control does not go away," says McGuire. The goal is to find healthy outlets for it.

Stand Up For Yourself

At the same time, it is important to retain your own control as well. "Let your care recipient know that they cannot run everything," says McGuire. For example, caregivers should set limits to the number of incidental needs filled per hour, such as filling a water jug or changing channels on the television. "When it is not an emergency, tell them they have to wait a few minutes. Non-essential care needs do not have to be filled immediately," she says.

That's good advice - whether your care recipient is always difficult or not.

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