

The Top Ten Things Caregivers Don't Want to Hear.... And a Few Things They Do

by Carol Levine, Director of the Families and Health Care Project

I've been a family caregiver for my disabled husband for nearly 17 years, and in that time I've been given all kinds of unsolicited advice, unwelcome criticism, and undeserved praise. I've developed a thick skin and some stock replies. But, I wondered, am I alone in feeling frustrated at the insensitivity of some of these comments, particularly when they come from casual acquaintances or marginally involved professionals? Apparently not! I sent a query to a caregiving listserv and other caregiving venues, and was deluged with responses.

I've edited, collapsed, and compiled the results, many of which match my own favorites but some of which relate to other situations. Not every response could be included and every caregiver will probably have a different list or a different ranking. Here then are my candidates (with a nod to David Letterman):

No. 10 – Doesn't Medicare (or your insurance) pay for that?

People who have no experience with long-term chronic care are unaware that Medicare and private insurance do not cover most of what is needed to keep a family member at home or in assisted living or nursing homes beyond short stays after hospitalization. Only Medicaid, which requires impoverishment, pays for long-term care, and even that program varies by state and is still biased toward institutional care. Enlightening the uninformed is tedious but perhaps serves an educational purpose. If these folks understood the financial burden and unending responsibilities of long-term care, then maybe they wouldn't say things like "Where are you going on your vacation? or..."

No. 9 – It must be hard to work and take care of your husband, so why don't you just quit your job?

My guess is that this is a question asked only of women, since men are presumed to have a greater personal and financial attachment to their jobs. Beyond the financial necessity, especially for women who are heads of households, work for many caregivers is an affirmation of their worth beyond caregiving, a source of friendship and stimulation, and a welcome balance to their lives. Others do leave the workforce, but at considerable cost to their current financial status and future retirement or employment opportunities. It's not a decision to be taken impulsively. A good friend or concerned family member can certainly help a caregiver weigh the options objectively.

No. 8 – Your mother belongs in a nursing home. OR: I could never

put my mother in a nursing home.

This is one of those statements that offends either way it is offered. The first formulation suggests that the caregiver is not capable of providing good care, or that Mother is dispensable. The second is a clear criticism of the caregiver who, after considerable anguish, decides that the only solution is indeed a nursing home. Well-wishers should avoid making quick judgments, which mainly serve to make the caregiver feel guilty. There is a place, of course, for candid discussion about whether the caregiver can continue to provide care at home. (Big exception: If Mother is truly being neglected or abused, then a professional intervention is in order.)

No. 7 – You have to take care of yourself; your husband (mother, father) needs you!

Of course, caregivers should take care of themselves; but why does it have to be linked to another person's need? Am I not worthy of good health for myself? And how exactly am I to find time to rest, exercise, prepare balanced meals, see the doctor, and do all the other things I should do? And if I don't do them and my health suffers, is it my own fault? Unfortunately, many caregivers do see themselves only as extensions of the person they are caring for, and still they don't take good care of themselves. And if a caregiver starts to explain why she doesn't follow all the good health rules, she is likely to be asked.....

No. 6 –Why don't you get your family to help out more?

This deceptively simple question steps on a huge emotional landmine. Some families cooperate without any hesitation or difficulty; in others, sharing responsibility is fraught with emotional traps. Some caregivers choose, for their own reasons, not to rely on other family members; others would like the help but either don't get it or find it comes with too many conditions. A trained professional can mediate and perhaps work out an acceptable division of labor. When some family members are not closely involved in care, they may say things like

No. 5 –I don't see what you're complaining about. Dad seems fine to me.

Elderly Dads and Moms have an uncanny ability to marshal their resources for the occasional visit of the out-of-town or uninvolved child, making the caregiving child's accounts of their behavior seem unreasonable. This statement has many variations: "Dad always got lost and drove too fast"; "Mom never could balance a checkbook"; "I forget things too." Less-involved siblings should make it a point to drop in unannounced and stay for a long enough time to see how Mom or Dad act under everyday circumstances.

No. 4 – I don't know how you do it. You must be a saint.

For a caregiver beset with frustration, depression, anxiety, and exhaustion, being told that you're a saint is decidedly unhelpful. (There may be some exceptions among those who aspire to martyrdom.) While this statement is surely meant to express admiration, it has the unintended or perhaps unconsciously intended result of distancing the speaker from the caregiver. After all, how many saints are there in the world? And if the caregiver is one, then the noncaregiver certainly won't be called upon to be one. Instead of sanctification, most caregivers would prefer a little help, which leads me to....

No. 3 -- Just call me if you need some help.

This is sometimes phrased as "I wish there were something I could do to help." Most caregivers have learned that imprecise, indefinite, offhand offers of help are expressions of good will but little else. The speaker feels better ---"After all, I did offer, and she never called," while the caregiver thinks, "What exactly does she mean by 'help'?" Friends or other family members who really want to help should make specific offers such as, "I'm going to the farmer's market; can I bring you some vegetables?" "I can stay with Mom on Saturday so you can do some shopping or go to a movie." "I know it's hard for you to get out for dinner, so I'd like to bring dinner to you one night this week." These are small things; the list could get progressively more complex and demanding. But whatever the offer, it should be firm and nonrefundable.

No. 2 --I know just how you feel.

This is another attempt at solidarity that fails. The caregiver is probably thinking, "No, you don't because sometimes I don't even know myself how I feel." Caregiving involves a complex and dynamic array of emotions, which each person experiences and internalizes differently. This statement shifts the focus away from the caregiver to the speaker, who frequently follows it up by talking about his or her own caregiving experience.

No. 1 -- God doesn't give you more than you can handle.

No. 1 on my list showed up surprisingly frequently on other people's lists, including members of the clergy, as well. This statement, sometimes phrased as "Don't worry, God will be good" is intended to be comforting, and for many people it may be. They need read no further. Why then do so many people find it upsetting? For me, the primary reason is that it is demonstrably untrue. Millions of individuals succumb to what God, fate, natural disaster, violence, or political, social, or economic turmoil have wrought. For caregiving specifically, studies have demonstrated that spousal caregivers are at increased risk of dying compared to their noncaregiving peers. And even if they don't die, their health and wellbeing are permanently affected. Unlike patient, long-suffering Job in the Bible, caregivers' losses are not repaid twice over when the challenge match between God and Satan is concluded. (What would I do with 6,000

camels anyway?) As Rabbi Gerald Wolpe, himself a caregiver, points out, Mrs. Job, the caregiver, is disdained and disregarded, and the new children given to Job do not replace those she has lost. From the Christian tradition, Kenneth Doka, a Lutheran minister and gerontologist, says, “Only the caregiver knows the extent to which he or she can bear a particular burden, and such comments could make the caregiver feel inadequate and unworthy.” Rev. Andy Calder, an Australian minister, says: “People hear these statements as clichés of judgement – of God being against them. The recipients are cast as people whose faith is perhaps suspect, as people who have perhaps incurred God's wrath for some misdeed, and as people who have no control over their circumstances: indeed, as victims.” For me, the most helpful approach comes from Rabbi Harold Kushner, author of *When Bad Things Happen to Good People*, who says: “[Bad things] do not happen for any good reason which would cause us to accept them willingly. But we can give them a meaning.” Prayer, spiritual solace, and religious rituals can help give meaning to caregiving, as can many other responses. Easy answers do not suffice.

So that's my “how not to” list. And here are a few additional suggestions for the “how to” list.

No. 3 – I have a friend who is having a lot of difficulty getting started as a caregiver. Would you be willing to talk to her?

Generally caregivers are very willing to help each other, as long as there are clear boundaries. Giving back what one has learned from painful experience can be gratifying. The decision, of course, depends on timing and mutuality of experiences.

No. 2 – I haven't seen you in a while, and I miss our (lunches, shopping, bowling, volunteering, whatever).

Caregivers are isolated, and phone calls can be welcome invitations to rejoin the world. Ideally, of course, the caller will follow up with a specific plan to meet.

No. 1 –How are you doing?

Some people ignore the caregiver altogether, looking the other way so that they do not have to have any conversation at all. Many people will ask about the ill person but not the caregiver. It's appropriate for family and friends to ask about the care recipient but they should be sure to follow it up with concern about the caregiver. And then they should follow the caregiver's lead. Sometimes he or she will want to talk about caregiving, and sometimes about something—anything--completely different. Listening well is the best support one can give, and the best support a caregiver can receive.

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