ASSESSING AND EMPOWERING THE CAREGIVER
or
YOU'VE BECOME A CAREGIVER – NOW WHAT?

Everyone is a CARE RECIPIENT. You might protest and say you don't need a caregiver or you might look around and say I'm all alone – who is there to care for me?

In one way or another we are part of a community, part of some circle of influence. You may have a large and very intrusive family, your family may be rigidly respectful of your privacy, you may live alone but have neighbors or professionals with whom you come into contact (even your druggist). Those people can have your best interests in mind OR they may have their own selfish purposes OR they might be generous with their time OR they could be burdened with their own responsibilities.

Periodically, it is wise to look around to see who is really there for you. If you find no one, NOW is the right time to put someone in place – a younger friend, a niece or nephew, and always one professional who understands your needs and values. The core advocate on your team is a geriatric care manager because he or she will always direct efforts according to your long-term expressed interests. [Some short-term interventions may not appear to match those wishes, but they are part of a pre-set plan to meet your goals.]

Almost everyone is also a CAREGIVER. You may be a parent, an adult child, a spouse, a business colleague who just happens to be available or someone enlisted when medical and social changes disrupt life. Most often, you are thrown into an unfamiliar role with no pre-established rules.

The two roles of a caregiver are:
1. To be the decision maker and
2. To act as the key to quality care.

Prior relationships often interfere with these responsibilities. A child is trained to respect his parents' financial choices; a husband is expected to respect his wife's idiosyncrasies. Suddenly, the caregiver must make a shift from one role to another and must define that role with different rules.

No matter how physically hard a caregiving responsibility may be, it is usually the emotional impact of the change which imperils both the relationship with the care recipient and the well-being of the caregiver. Without a clear understanding of the entire process – the nature of illness, the availability of resources, the know-how to navigate the medical system – the caregiver is flailing her arms with her shoelaces tied together.

The caregiving process starts with the caregiver, not with the care recipient. How can that be when professionals are ethically bound to focus on the needs of the client? It's because that circle of influence (which can be the source of the solutions) is most often THE PROBLEM. When there are good intentions backfiring or uninformed opinions or just confusion at the caregiving end, all help for the care recipient gets diluted through emotional obstructions. The difficulties arise because the relationships in our support network are usually developed at an earlier time – as parent/child, as spouse, as friend. <u>When health and financial circumstances change, those roles may need adjustment. And with that, comes a change in the rules.</u>

Just think how hard the most mundane changes are for us. We have always worn our hair one way, have always shopped at one particular store, eat the same thing for breakfast every day. If we are suddenly asked to make a change, not of our own choosing, we will resist, sometimes just to maintain our autonomy. But aging is nothing but changes. These changes include loss of our ability to handle "instrumental activities of daily living" – driving, paying bills, making appointments; then "activities of daily living" – showering alone, preparing meals; and many times changes in behavior – memory deficits, mood swings. The old roles and rules no longer apply.

Each family and every relationship is different. It is important to recognize those different "cultures" and find a unique strategy for making these role and rules shifts.

One's role changes along a spectrum of activities:

1. Caregiving begins as soon as you do some activity previously handled by the loved one and outside of your customary role – writing checks, preparing the marketing list.

2. Caregiving takes on its own identity when the demands increase so that you are not only supporting the other's activities, but asking them to step aside so you can complete the job. Spouses get in the most trouble in this phase because they continue to "just do whatever is necessary", not taking account the time and energy and stress of the extra responsibilities. If a perceptual shift is undertaken at this time, you are freer to embrace your new role and function more happily and productively.

3. When hands-on care is necessary, especially toileting and bathing, many people start to consider alternate living options. Often a setting tailored to your loved one's needs is a kinder choice than your continuing to "patch things together" in the home. This freedom also allows you better quality of time to do your real job which is making clear decisions on behalf of your mother or husband.

4. Acting on the idea of a move to a specialty environment is especially difficult if the caregiver has not progressed through an adjustment to his role and the rules applying to the new relationship. He is "stuck", conflicted and very weakened in his ability to take the best care of his family member and himself.

Caregiving requires two kinds of change:
The BIG CHANGE is to alter your ROLE, your identity in the relationship
The SMALL CHANGE is to tweak the RULES which apply to that role as circumstances dictate.

Caregivers need to be educated, supported, celebrated for their new role and relieved of as much emotional and physical pressure as is possible within the financial and social framework of their intimate circle.

Written by
Anne Harbison-Lucas, MS, CMC, Certified Geriatric Care Manager
AHL Services and Daisy Ladies
5634 E 2nd St
Naples, CA 90803
Tel: 562-244-5617
Anne@AHLServices.org