

## Getting a Handle on Caregiving and Your Life

People often find themselves in a demanding caregiving role at a time in life when they have limitations. For example, for many, involvement in the care of an elderly parent often occurs in the midst of a mid-career transition or at the beginning of retirement. Additionally, I have known many adults who are intensely involved in raising children while also contending with the demands around the care of an elderly or disabled parent or relative. For many, caregiving results in simultaneous feelings of burden, confusion, and guilt. Let's take each of these feelings and deal with them separately.

### **Burden**

The two most important things to remember about caregiver burden is that (1). It can end and (2). It can at least be relieved to a greater degree than you think is currently possible.

### **Confusion**

Confusion about the health-care system and the options for services is an understandable and seemingly universal experience for caregivers. One big way to resolve this confusion is to know how to quickly identify the key people and places where concise and understandable information can be found.

### **Guilt**

Guilt can be an ongoing feeling for many caregivers. I recently had caregiver tell me that she feels guilty whenever she finds herself focusing on somebody other than her frail and elderly mother.

The first big step that you can take right now to alleviate all three of these feelings is to get clear about the entire caregiving picture. **The easiest way to do this:** Write a 1-2 page summary of the issues facing your parent, relative, or friend who receives care. In this summary include your understanding of the following:

(Please do not get overwhelmed with the list below. Just write what you currently know and fill in the blanks later. You will likely be surprised as to how much of this information you can easily recall).

a. Your impression of what the elderly or disabled friend or relative currently desires for a lifestyle both now and in the future. Does he or she wish to remain at home? If so, are they willing and able to accept care and pay for it? Would they consider moving to an assisted living or nursing facility?

b. Your understanding of the elderly or disabled person's income and assets. This might include income from Social Security, pension, rental income, dividends from stocks or mutual funds or income from annuities. Value of CDs or IRAs. Additionally, who owns their home? Estimate the fair market value of the home and attribute that value to him or her, based on how much ownership they have.

c. Each health and mental health problem and how it affects function. For example, "arthritis makes my mother's walking unsteady and painful." Another example, "my Dad can no longer be left alone due to his dementia."

d. Write down information about each medication, the dosages and your understanding of potential or current problems with side effects.

- e. All medical and mental health providers who are currently or recently (in the last three years) involved in the care of the elder or disabled person. This list may include physicians, nurse practitioners, mental health providers (e.g., psychiatrists, psychologists or therapists), rehabilitation therapists (e.g., physical or occupational therapists, speech-language therapists), podiatrists, ophthalmologist and optometrist.
- f. List all financial and legal professionals. This typically includes attorneys, accountants and insurance professionals. If you know what they charge, write this down as well.
- g. Any social service providers such as case workers or staff from an area agency on aging, adult day health program, mental health agency or an agency that assists people with physical disability.
- h. List anybody who is currently providing care. This list might include paid or unpaid people who assist with bathing, dressing, meal preparation, shopping, cleaning and companionship. Include both those who are regularly scheduled to provide care and also friends and family members whose involvement is more incidental and perhaps more social in nature.
- i. Your opinion of the current plan of care and the resulting quality of life for the elderly or disabled person. Is there enough care? If not, why? What additional care is needed? Is the elder able to engage in enjoyable activities? If not, why? Is the elder interacting with and or cared for by people who are competent and respectful of him/her?
- j. Your general opinion about the elder or disabled person's current and future appropriateness for living where they currently are. Is their current living arrangement safe? Healthful? Affordable? Is more care needed? If not, is there some place more appropriate to consider either now or in the future? Could there be any family, legal or financial issues that would emerge around an increase in the level of care or a move to an alternative residence or facility?

The above exercise is designed to help you determine what you know and do not know. Determining this will quickly start you down the road of taking action that should lead to you reducing your experience of burden, confusion and guilt. Please take the time to write the summary as this will become the basis for getting a handle on caregiving and ultimately on your life

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