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# Eight Steps for Family Caregiving, Part 1

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It's the most natural thing in the world to struggle as a caregiver with a sense of chaos in dealing with an elderly parent's medical emergency or serious chronic illness. Here is where a positive and proactive approach can really help adult children caring for aging parents. Our care-manager method, which focuses on eight basic activities -- or steps -- that we will outline in this blog, has helped many families navigate the complex terrain of family caregiving and find practical solutions, as well as moments of joy, in caring for aging parents.

We are going to write about each of these activities in greater detail, and here is a preview:

## **Tobin 8 Steps for Family Caregiving**

1. Understanding doctor's recommendations and asking productive questions.
2. Becoming health literate regarding medical terms and health information.
3. Getting information on non-medical topics (home care, insurance, healthcare finances).
4. Linking medical and non-medical needs and creating an active problem list.
5. Obtaining guidance for solving specific family caregiving problems.
6. Dealing with emotions for both parent and caregiver.
7. Finding and hiring tangible support and services for your parents.
8. Extended planning for your parents foreseeable and long-range future.

Source: Care Support of America

Our method has been developed over decades of working with patients, their families, and healthcare providers -- and proven in five major studies. Understanding these steps can help you face worries, concerns, and fears, come up with a plan, and be successful in getting family members to work together in keeping your parents in a safe, comfortable, and dignified environment. The unfamiliar medical and non medical environment of family caregiving can be managed when you decide to gain as much control as possible within your family situation.

We'll deal with each step in greater detail in this and future blogs, and also provide a checklist for quick reference.

## **Step 1: Working with Your Parent's Doctors**

## **Keeping the Doctors Coordinated**

Your parent may be seeing more than one doctor, and it's important to know who your parent's primary treating physician is. Sometimes this is a doctor who has not known your parent for a very long time. Primary-care doctors' offices are usually very busy, and most do not have the time, staff, or technology in what can be called a "medical home" to help coordinate your parent's chronic illness or to help you fully understand all the treatment options. A professional care manager can help, but the doctor's office is where you must start if you intend to figure out the details and come up with a plan to manage the illness and care between visits. Of course, your parent has to give permission to their doctor to talk with you and release any confidential medical information.

So, start by asking the primary-care doctor some simple but crucial questions:

*--What is my parent's condition?*

In coordinating your parent's chronic illness needs, you need accurate information and direction from your parent's primary-care doctor. You'll need to understand your parent's diagnosis (or diagnoses -- many elderly people have more than one condition). This is the first step in understanding the specifics of your own situation as well as that of your parent.

Psychologically, simply knowing what these conditions are, and the relative severity of each, will help keep you feeling more grounded and less powerless.

*--What is the prognosis?*

Once you have the diagnosis, you'll want to get the prognosis -- the doctor's prediction of the illness's probable progress over a period of time. Your doctor may or may not volunteer the prognosis -- don't hesitate to ask. Obviously, the prognosis will depend on the disease, and it may change over time. This is a difficult one to face, since at some point we have to face the inevitability of serious illness and dying. But it is far better to know the facts, so that you and your parent can be prepared.

*--What is the treatment plan?*

Your next questions for the doctor involve the treatment plan -- will it involve surgery, radiation, chemotherapy? Are there any routine outpatient procedures? What medications will your parent need and how often? What are the side effects? What can be done to make your parent the most comfortable possible, for the longest length of time?

## **Involving the Family**

In order to get the best information about diagnoses, prognoses, and treatment plans, you'll want to establish the roles of various family members in communicating with your parent's doctors, the doctors' staffs, and all the treatment providers. In most families, one person is the primary caregiver -- often it's the spouse of the sick parent, and just as often it is one of the adult children.

It's important for your family members to all discuss who will have the primary caregiver role, and what roles the other family members (or close friends) will have. There are plenty of things to do:

*--Who will be the person to contact other family members about the evolving situation?*

*--Who can commit one day a week to caregiving in the home so that the main caregiver can get some rest?*

*--If the primary caregiver is unable to communicate with the doctor's staff and distribute information to the rest of the family, who in the family can take on this role?*

The purpose of all this is to create an "activated family unit," partnering with your parent's doctors and the doctors' staffs. The family can then depend on the designated family caregiver to get the information from the doctors and relay it to everyone else. With one family member as the point person, you will develop a stronger working relationship with the doctor's office.

The primary caregiver will also need to coordinate the information from multiple doctors' offices, integrate test results and treatment plans into the patient's and family's daily activities, and plan home-based care. It's a partnership that will make the most of everyone's limited resources.

### ***In the Doctor's Office***

A doctor's office can be intimidating and you may not have the time to ask all the questions that are important to you. So you need to start with a determination not to be intimidated. You and your family should develop a simple written list of questions, and make an appointment with the doctor's office to discuss them. It doesn't need to be a long appointment, but it is important.

Sometimes, doctors will refer you to handouts of literature, and it's helpful to have read those materials before your conversation. Then you won't be sidetracked and can still ask your pressing questions that the literature didn't answer.

Here are some questions you might ask, as well as some ideas on how to be proactive and clear with the doctors. You should also include questions other family members might have:

*--Can you cure the disease or is it going to get worse?*

*--Is the illness acute or chronic?*

*--What will it feel like if it gets worse and how can you help my parent be comfortable if it does?*

*--Can you speak a little more slowly so I can be sure I have it right?*

*--Can you put that in lay terms so that I can be sure I understand what you are saying about my mother's care?*

*--Do you have a picture that will help me get the idea?*

*--If I draw a picture of it, I will remember it better and can explain it better to other family members. Can you help me do this?*

*--I thought I heard three different points in what you said. Can we go over each of them briefly one more time?*

*--Can I repeat to you what I heard so I can confirm that I have it right?*

*--Sorry, but I don't understand clearly what you are saying even though I know you explained it well. Can we go over it one more time?*

Be sure to take notes on everything the doctor tells you. This won't be your last list of questions, but it's a start. As an illness progresses, being prepared and knowing how to work with doctors' offices, hospitals, and health-related services will help you anticipate obstacles and critical issues ahead.

In the next blog, we'll talk about how to wade through the vast amounts of medical information that are now available (some useful, some not) to fully understand the needs of your ill parent and become health literate.

For more information, go to <http://www.caresupportofamerica.com>.

Checklist: [5 Tips for Working with Your Parent's Doctors](#)

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