



# Creating Your Informal Care Team

## Things to Keep in Mind

As difficult as this may sound, my best tip is to ask for the help you need. Don't hint. Don't whine. Don't blame. Don't bring up past issues. Be very specific about what you need, when you need it, why you need it, why your loved one needs it. Put it in the form of an "I" statement; i.e., "I need help getting Mother to her doctor's appointment." I know from experience that sometimes I think my family should know to help without my asking, and maybe they should. Don't wait, don't wish; simply ask. If they say no this time, ask again. If they can't do what you need, ask if they have ideas of how to get it done.

**L.E., family caregiver**

## Taking on Too Much

If an exhausted caregiver continues to try to provide everything needed without asking for help, those around assume that they are fine; they believe if the caregiver weren't fine, they would surely stop and ask for help. As a family caregiver, you may become angry and feel abused and victimized. You may feel that others should know that you need help; but the truth is, if you don't ask, no one will know. The people around you may not be unwilling or uncaring; they just aren't mind-readers.

Don't expect family and friends to know how you are feeling. Be specific in seeking their support, such as babysitting, carpooling, a cooked meal, and hour or two for yourself.

## Caregiver Codependency

As a caregiver, you are most likely a naturally giving person. This additional responsibility of caregiving may seem natural to you. Sometimes, this is accentuated for people who are codependent. People who are codependent have a history of setting poor boundaries and ignoring healthy limits, which are important to



## Preventing the Loss of Friends

### Comments from Family Caregivers

We must do our best to educate others about our loved one's disease or illness as many are unaware of or even fearful toward progressive medical conditions. You can write a letter to family members and friends about the diagnosis and how the patient needs help and support. The letter dispels fears and opens up communication.

Let others know how they can help. Keep a list of ideas handy and be specific so others can easily step in to assist you. Friends can serve as respite providers, drivers, phone companions, errand helpers and visitors. One neighbor offered to take a man out for a ride and to a coffee shop every Saturday morning so that his caregiver could have her hair done and pick up groceries. Both parties were served with just a few hours of help each week.

Nurture present relationships, reach out for new friendships and show appreciation to those who have been able to stand by you through the years. A handwritten thank you or verbal acknowledgment goes a long way to express gratitude to others and encourages them to stay involved.

Support groups can be a wonderful place to meet other caregivers and form new friendships. I recently learned of two couples, each caring for a spouse with Parkinson's disease, who now meet monthly to enjoy lunch and socialize before attending a support group together. They share a common experience and are able to understand each other's needs.

*You must take care of yourself. It is an act of love. You should take care of yourself so that you are really nurturing yourself to have the best to give to others. It is important to take care of one's own self—not as self-defense, not as an act of revenge or rage, but because it is the right thing to do. If there is no water in the well, you cannot share it with people. If there is no food in the refrigerator, you cannot feed people. If there is no energy in your body, if your mind is in a state of constant distraction or dismay, you cannot be of service to people. And you are not going to be the best company, either.*



Phylicia Rashad  
Actress and care advocate

## When Family Members Won't Help No Matter What

Frankly, sometimes even our best efforts will not ensure that all family members will do what is requested of them to support our mutual loved one. Insurmountable emotional issues of the past, mental illness or just distance may play factors in their unwillingness or inability to help. In some cases, the smallest help is all that is necessary. "Please, just call Mom (Dad) on Sunday to talk for a half hour" or "Can you send a small check monthly towards our loved one's support?" It is as crucial to know who you cannot count on as you build your informal care team as it is to know on whose support you can count. Once you have done all you can to elicit help from certain friends and family members and none is forthcoming, it is best not to expend much emotional energy on their decision. Try to understand as best you can and move on.