



Fact Sheet: **Twelve Steps for Caregivers**

Introduction

The Twelve Steps were originally developed as the heart of the Alcoholics Anonymous Program in order to provide persons with a unity of purpose and guidance for individual growth. Since that time, professionals and self-help groups have used or adapted these twelve steps for various purposes. The Twelve Steps developed by Alcoholics Anonymous focus on three different areas. **First**, they acknowledge that human resources such as intelligence, knowledge, strength and hope are not enough to help persons solve problems. **Secondly**, they focus on the need to accept the help of a Higher Power to guide thoughts and actions. **Finally**, they suggest ways that Power can be brought into one's daily life so that action can be taken.

In our research with caregivers of persons with dementia, one caregiver wife reported that she was applying the Alcoholics Anonymous Twelve Steps to her caregiving experiences and challenged us to incorporate some of these ideas into our eight-week intervention program. We reviewed caregiver responses to our structured research interviews and noted additional comments that caregivers frequently made. Out of these comments, we compiled the Twelve Step for Caregivers. We have distributed a list of these steps to caregivers who participate in our educational support

groups. Our approach in using these steps for caregivers has been flexible. We review these steps early in the eight-week program and incorporate them throughout the following sessions. While the Twelve Steps originally were proposed for caregivers of persons with dementia, we propose that they are applicable to caregivers in other situations.

The steps for caregivers are summarized below and are discussed in more detail in the remainder of this article.

Twelve Steps for Caregivers

1. Although I cannot control the disease process, I need to remember I can control many aspects of how it affects my relative and me.
2. I need to take care of myself so that I can continue doing the things that are most important.
3. I need to simplify my lifestyle so that my time and energy are available for things that are really important at this time.
4. I need to cultivate the gift of allowing others to help me, because caring for my relative is too big a job to be done by one person.
5. I need to take one day at a time rather than worry about what may or may not happen in the future.

6. I need to structure my day, because a consistent schedule makes life easier for my relative and me.
7. I need to have a sense of humor, because laughter helps to put things in a more positive perspective.
8. I need to remember that my relative is not being “difficult” on purpose; rather that his/her behavior and emotions are distorted by the illness.
9. I need to focus on and enjoy what my relative can still do rather than constantly lament over what is gone.
10. I need to increasingly depend upon other relationships for love and support.
11. I need to frequently remind myself that I am doing the best that I can at this very moment.
12. I need to draw upon the Higher Power, which I believe is available to me.

Discussion

Step 1: I can control how the disease affects my relative and me.

Once the diagnosis of an irreversible dementia has been made, caregivers soon learn that modern medicine knows very little about the cause, treatment and prevention of the disease. It is important that caregivers understand that Alzheimer’s is a chronic and ultimately terminal disease. And while caregivers may learn about caring for persons with dementia from numerous books and articles, it is important that they realize which aspects of caregiving they can control and acknowledge

aspects over which they have no control. Ultimately, no matter what the caregiver does, the disease process will not change. However, caregivers can learn to control such things as disruptive behaviors. Some caregivers have reported that the Alcoholics Anonymous Serenity Prayer has been helpful to them. It is as follows:

God grant me the serenity to accept the things I cannot change, courage to change things I can and wisdom to know the difference.

Step 2: I need to take care of myself

For most caregivers, this is a difficult lesson to learn. Some caregivers feel that they must “always” put other persons first and that it is selfish to think of doing things for themselves. They must learn that in order to continue providing care for their family members, they must first take care of themselves. Therefore, caregivers need to give themselves permission to “indulge” in such things as obtaining relief by using sources of respite and by involvement in outside activities that they both need and enjoy. Oftentimes professionals or other persons play an important role by giving caregivers permission to take care of themselves.

For some caregivers, self-care becomes a real issue when they can no longer assume full-time care and need to consider in-home assistance or nursing home placement. These decisions may be very difficult as caregivers may feel that they are failures, are selfish, and are not keeping a promise made to the care receiver. Some caregivers need assistance to realize that the demands of providing care for a person with dementia may exceed individual resources. They need to see themselves as important and to

acknowledge their abilities and preferences when making caregiving decisions.

Step 3: I need to simplify my lifestyle.

It is essential that caregivers be able to identify what is most important, what should be taken care of immediately and what should receive most of their attention. As caregiving responsibilities take up more of their daily lives, other activities need to be adapted or dropped. If caregivers wish to maintain outside activities and interests, they will need to lower unrealistic expectations they may have of themselves.

Step 4: I need to allow others to help me.

This step can also be very difficult for caregivers who have lived most of their lives thinking they “should” be independent, and for those who view asking for help as a sign of weakness. Along with cultivating the gift of allowing others to help, they need to learn how to actively ask others for help. Caregivers often report that friends say, “Call me if you need help.” We encourage caregivers to keep a list of activities nearby, and when this type of offer is made, the caregiver can readily say, “I need help with...” Presenting others with a variety of specific tasks allows them to volunteer assistance and accommodate their resources.

Step 5: I need to take one day at a time.

This slogan is borrowed directly from Alcoholics Anonymous and is commonly used by family caregivers. It reinforces the importance of thinking only about the day’s challenges and helps caregivers to focus their energies on what is most important in the short term.

It also lessens feelings for being overwhelmed when looking ahead to

concerns, which may never develop. It has been suggested that having dementia is the ultimate existential experience. Persons with dementia have a patchy memory of yesterdays and a poorly anticipated future. For the person with dementia, it is essentially the “here and now” that is significant -- a reality to which caregivers must adapt.

Step 6: I need to structure my day.

Because of the memory impairment brought about by the disease, it is important that the caregiver develop a sense of structure, routine and rituals for their family members. In so doing, the care receiver feels more a sense of safety and security and caregiver can use their time and energy more efficiently.

Step 7: I need to have a sense of humor.

Caregivers have often reported that a sense of humor helps them through a difficult situation. One caregiver reported, “I choose to make this a humorous headache.” Another caregiver said, “You have to laugh, you can’t cry all the time.” Maintaining a sense of humor means that caregivers have to be objective enough to see the irony in painful situations.

Step 8: I need to remember that my relative’s behavior and emotions are distorted by his and her illness.

In our research, we found that while caregivers generally intellectually understand dementia as a disease process, they are more likely to take it personally and feel that the person is being “difficult” or is “getting back” at them when disruptive behaviors occur. It is important to help caregivers keep an objective viewpoint about their experiences and to be able to attribute

to the disease what rightfully belongs to the disease, and not simply to the relationship.

Step 9: I need to focus on and enjoy what my relative can still do.

In the professional literature, much emphasis has been placed upon helping caregivers deal with the impaired family members' "problem behaviors." Much less, emphasis has been placed on understanding who the person was and still is. Caregivers have frequently reported that what helps them through the process of caregiving is to be able to see who their relative "is" in the present, as well as appreciate who this person "was" in the past. Enjoying the good moments for what they provide is commonly seen by caregivers as a way of helping themselves through their present difficulties. Focusing on what the person can still do also maintain care receiver independence and prevents "excess disability."

Step 10: I need to depend on other relationships for love and support.

As the dementia progresses, the care receiver is less and less available to the caregiver as he or she has been in the past. Caregivers often report that one of the most difficult aspects of caregiving is the loss of this person who once "was." A daughter remarked, "We are losing my mother piece by piece."

As this process evolves, caregivers must increasingly look to others family members and friends for the love and support that the impaired family member once provided. Caregivers need to understand that a desire to be cared about and supported by others is a

normal human response, and that it is essential to have these needs met in some way.

Step 11: I need to remind myself that I am doing the best I can at this very moment.

Caregivers must realize that they will not handle every situation "perfectly," and that at times they will become impatient and angry with the care receiver. They will always be able to see things they may have done differently or better. However, it is important for caregivers to acknowledge their human limitations, develop a sense of acceptance of themselves, and accept how they have manages a particular situation. While "second guessing" and feelings of guilt care common with caregivers, it is important for caregivers to immerse themselves in positive reinforcement so that their precious time and energy at not siphoned off into thoughts that are self- defeating.

Step 12: A Higher Power is available to me.

Many caregivers report that their sense of High Spiritual Power has assisted them through many difficult situations, and that this same power has been what has helped them to find meaning through their caregiving experiences. More recently, caregivers have reported that a book of prayers specifically related to Alzheimer's disease has been a useful resource.

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