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ABSTRACT

Based on interviews with 20 primary caretakers (the main person responsible for elderly relatives with chronic illness or disabilities) this pamphlet was written for family members who are caring for older relatives, and may also be helpful to professionals and paraprofessionals who work with the elderly and their families. The two main sections of the pamphlet deal with the thought and feelings of caretakers of the elderly, and practical information for providing daily care. The first chapter, The Meaning of Caretaking: A Variety of Perspectives, covers 11 separate areas and includes coping suggestions for the issues discussed, which include independence, emotional involvement, apprehension, guilt, anger, loss, and responsibility. The second chapter, What Caretakers Do, presents a discussion in each of seven areas arising from the actual work of primary caretakers. Topics presented are chores, emotional support, referrals, transportation, and recreation. A brief, final section touches on suggestions for alleviating the stress of primary caretakers. (PAS)

CARING FOR ELDERLY RELATIVES:

Ideas From Families Who Do

by Catherine Strong, Ph.D.

Bellingham, Wa. - February, 1981

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INTRODUCTION

Although there has been much talk about elderly people abandoned by their families in times of need, it is more often the case that families do care for their aging relatives. When an older person becomes ill, the family's help is likely to be crucial in maintaining that person in the community and avoiding a move to an institution (for example, a nursing home). In order to learn more about families' roles in such a situation, the Federal Administration on Aging funded a small research project. The information in this pamphlet comes from interviews conducted for that project.

This pamphlet is written specifically for family members who are caring for older relatives, but it may also be helpful to professionals and paraprofessionals who work with the elderly and their families. In order to learn more about caretaking, I spoke with 20 people, all of whom are primary caretakers (the main person responsible) for elderly relatives with chronic illnesses or disabilities. Some of the elders live alone, some live with their spouses, and some with their families. All of the family members I spoke with live in small towns or in rural areas of Northwest Washington State. They vary in income and education. Most are women, but four are men. Ten are White and ten are Indian. They are the wives, sons and daughters, grandchildren, nieces and nephews, sisters and daughter-in-laws of the elderly persons. Many of the elderly relatives have more than one health problem; heart conditions, strokes, arthritis, diabetes, cancer, alcoholism, vision or hearing loss, chronic organic mental disease ("senility"), depression, and loneliness are among the problems named by the family. Because these people experience a variety of situations, they can introduce you to a variety of ways to think about caring for elders.

If you are helping out someone who is old and ill, chances are good that someone's statements in this booklet will capture how you, too, are feeling. These people do have a special knowledge about caretaking because they are doing just that. When I asked one woman about when advice in books or magazines is useful, she replied,"Sometimes they are helpful and sometimes I think that they don't know what they are talking about. If you haven't lived it, you don't know. If it's down to earth, natural, if they have lived through it, it is helpful."

There are two main chapters in this booklet. First, how do these people think and feel about the situation? This chapter includes some suggestions about how to cope with difficulties around particular issues. Secondly, what is it that caretakers actually do? For family members who want more practical information about providing daily care, especially for elderly who show memory loss or confusion, I recommend the Family Handbook, written by Nancy Mace and Peter Rabins and published by Johns Hopkins University Press.

The pamphlet is written so that you can read one section within a chapter at a time, and you need not read the sections in a particular order. If you are providing or expect to provide care for an older relative who is ill, and you want to hear what caretaking is like for others who are 'living through it', this booklet is for you.

This booklet is available ~~without cost~~ to residents of Whatcom County (Washington State) from the Area Agency on Aging in Bellingham (676-6749) and the Whatcom Counseling and Psychiatric Clinic (676-9210). If you live in Whatcom County and would like to talk to someone about providing care to an elderly relative, or to learn about resources available to senior citizens, call Caty Strong (676-9210) or Jim McRandle (Information and Assistance Program, 733-4030). If you live outside of Whatcom County, your local Area Agency on Aging or Community mental health clinic should be able to answer your questions.

I would like to thank Senior Center staff, the Area Agency on Aging, the Whatcom Counseling and Psychiatric Clinic for their interest in this project; Tom Moore and Richard Spitzer for their editorial comments; and Vicki Lee for her editorial, data analysis and typing services which were helpful throughout the project. Special thanks to the 20 people who gave me their time and answered my many questions with much thoughtfulness, patience and good will.

The author of this pamphlet was Principal Investigator of AoA Grant #90-AR-2076. She received her doctorate from the University of Chicago (Committee on Human Development) and is the Geriatric Services Coordinator at Whatcom Counseling and Psychiatric Clinic in Bellingham, Washington.

CHAPTER I

THE MEANING OF CARETAKING: A VARIETY OF PERSPECTIVES

One of the basic goals of both this pamphlet and the study is to look more closely at the experience of caretaking. One way of answering this question is to look at how people actually think and feel about the caretaking situation. How do they talk about caretaking? What are the main issues or themes that they address? In order to find out about the themes of caretaking, I looked at how people described their thoughts and feelings during the four to six hours I spoke with each of them.

Some themes were mentioned by all 20 of the people I spoke with; others were mentioned by only a few. The themes will be presented according to how many individual caretakers mentioned each one during our talks, starting with the ones mentioned by the most people. Some of the concerns which you will see expressed here will be familiar to you, whether or not you agree with the person's point of view about this topic. In other cases, you may decide that the topic mentioned by some of the caretakers does not fit your situation or the situation of other people you know. However, seeing how others view caretaking may open up new ways for you to see your situation and yourself as caretakers. Since all the topics discussed here were mentioned by people who are caretakers, you can trust that they do apply to someone's situation.

Independence

All of the people I talked with mentioned independence or dependence as a concern. This is not surprising, since by its very nature, the act of one person caring for another who is ill means that one person is dependent on another in some ways. It is also an issue because we usually think of younger people, especially when they are children or very young adults, as depending on their elders, possibly for advice, emotional support, or financial aid. But, when an elder is ill, most often they are relying on someone who is younger to provide care for them. This change is especially evident when grown children are caring for their elderly parents. At one time that child was dependent on the parents for all needs. But now that the parent is both old and ill, the child must adapt to being depended upon.

Another aspect of this topic is that many people have a value on autonomy, that is, they believe that they should be self-reliant, and want to be as independent as possible, whether they are young or old. The value on independence and autonomy is something that may vary according to one's cultural background, but in this country, independence and autonomy are generally highly valued. Therefore, people notice whether someone acts independently, with self-reliance and autonomy, or shows dependence on others.

Following are two examples of caretakers who talk about valuing their own independence or the independence of their elders. The first example is from a woman who lives with her mother:

> "I have power of attorney, but I haven't done a thing. I think she needs that independence. I think the more independent she stays, the longer she'll live. Sometimes I've gotten quite cross with her when she wants to be with me all the time because I have my own life. I need independence, too. I want that freedom, too... The fact that she's got an active mind, and that she's an independent person, I like that."

This example is from a man who is caring for his mother. He, too, places a high value on independence:

> "It is hard for me to baby anyone. I won't encourage them to be overly dependent. If I hadn't been hard-nosed, she'd probably be in a wheelchair now... That's the difference between my wife and I. I'm so damned independent. I don't ask for help, whereas my wife, she knows it makes people feel good to ask them for help ... Maybe by the time I get old, they will go back to the old Indian traditions, take the old man out and let him die. I wouldn't want to be totally dependent on anyone."

Here a daughter who cares for her mother, but does not live with her, talks more of dependency than of independence:

> "She's just weak mostly. She can't do by herself. When she had that attack, she was helpless. When I walk in with her meals and I see her, I think, she really needs me."

Clearly, people think in different ways about independence. When a person highly values his or her own autonomy and that of other people, being a caretaker may be a difficult situation. Some people express very strong feelings about it, like the man who hopes that people would "take the old man out and let him die." This is not an uncommon view, even if it is unlikely to be carried out in actual life. Caretakers may be reminded, by their elder's illness and increased dependency, that this may be their future also. Other people are more comfortable with mutual dependence, and derive some pleasure from realizing how much they are needed.

These are two different patterns. In the first type, those who highly value independence are likely to encourage independence on the part of their elder. This may fit very well with the elder's point of view and may help him or her to lead a more active and independent life. Sometimes it seems easier to do a chore for an elder, particularly if it takes him or her longer than it does for you; however, this may ultimately increase your chores and decrease what the elder can do. As is true for any of us, when people learn to rely on someone else to do things for them, they may lose their motivation and/or their skills in that area, at least temporarily. Determining what an older person who is ill can or cannot do is often difficult; in such cases it would be wise to consult their physician (or a mental health specialist, when applicable) to understand better what they are capable of doing.

If both you and your relative value independence, physical space can be important, as many caretakers mentioned. One woman explained: "You have to consider the facilities. We have a big, roomy house. You need your moments of privacy and so does the person you are caring for." For those caretakers who would like some help but are reticent about being dependent on others for that help, it may be reassuring to know that most of the people I spoke with suggested that caretakers"make use of the facilities available for the elderly." One woman who usually values being self-reliant advised:

> "Don't be afraid to ask for financial help when it is needed. More and more with this economy people who have never asked before may now ask. There is nothing wrong with that."

A second type of pattern is when a caretaker gets a great deal of satisfaction from feeling needed and helping another person. For instance, one woman who is caring for her aunt said, "I'm the type of person, I've got to help somebody. And with my mother and father gone, I've just shifted that help to my aunt. So, my needs are being met as well as hers." When a caretaker wants to help to an extreme, so they do almost everything for the elder, this can discourage the elder's own ability to function, as mentioned above. But, when the limitations of the elder are both real and great, getting satisfaction from helping can make the job easier for the caretaker.

Each pattern has its pluses and minuses, depending upon the situation and upon the particular people involved. Also, the two patterns are not mutually exclusive, and you may remember having felt both ways.

Emotional Involvement

Like the topic of independence, all the people interviewed referred to the issue of emotional involvement. Since they all are related to those for whom they are caring, and have chosen in some manner to be the primary caretaker, it is not surprising that the issue of closeness and commitment, or distance and lack of personal involvement is an important theme here. Two men, who are caring for an uncle and a father, note the importance of emotional involvement:

> "I mean once the elders get the feeling of not feeling wanted, then they start getting lonely... The younger community members have to get more active with the senior citizens... It's like high school. You were either in or out, and they must feel that way... That's the most important thing, to feel noticed."

> "I suppose it is -- the feeling of family, or feeling of belongingness. We've been pretty close...family fellowship."

A woman who is caring for her mother is more concerned with limiting her involvement:

> "You have to have a certain amount of detachment and toughness. You can't get too emotionally involved... let your common sense rather than your emotions prevail."

Thus, both sides of the coin are represented. Emotional involvement can be seen as a positive goal and a need that we all have; for others, the more important point is not to get overly involved.

Some caretakers are especially aware of the elder's need to maintain involvement with other people. Some people mentioned the responsibility of people in the community to make their elders feel involved. As more and more people become old, it is likely that they will command more attention in their communities and in the country as a whole. In the meantime, how do caretakers cope with their particular concerns about their elder's involvement or lack of involvement?

When older people become ill, they often find it difficult to remain socially active. If they still wish to be involved in activities, there are often transportation and planned activities available. If they do not wish to be actively involved with others, it is worth asking yourself whether or not they were actively involved in the past. If people have been "loners" all their lives, this may be the lifestyle they prefer. For persons who were formerly active, but recently have become disinterested in other people or activities, this is a change worth discussing with the elder's physician or with a counselor; there is often a reason for the disinterest and the former activity level may be restored.

Some people talked about the closeness or distance of their own relationship with their elders. As the quote above implies, there are those who find too much involvement upsetting: they may find it difficult to balance the closeness and distance to their relatives to the level that feels most comfortable for them. (If this is an area of concern for you, you might want to read the section on Conflict.)

Apprehension

Almost all the people I spoke with talked of feeling some apprehension about their elderly relatives. They felt fearful, tense, worried or concerned as opposed to feeling free of fear; they expressed doubts or anxiety as opposed to feeling relaxed, secure or relieved. Caretakers also spoke of trying to avoid distressing the elder. Here are some of the ways that people talked about feeling apprehensive:

> "Like I said, it was more or less a worry because she wouldn't cooperate. A nervous strain. I can't stand a lot of pressure any more. I know it made my blood pressure go up... I'm relieved to hear she's getting along well."
>
> "Going to the store bothers her. She gets uneasy, nervous... When we leave her we're afraid she'll climb up and do something to hurt herself ... I'm afraid to say 'no' to her in case she gets distressed."

Because feelings of apprehension may come from many sources, advice about how to feel less tense or fearful may take many directions. One way to deal with the stress causing the anxiety is to try to change the situation, so that whatever is causing the stress will do so no longer. For instance, if one's relative is ill, a person might take the relative to the doctor and get medical care which will correct the illness. Or, if a relative is living with the caretaker and the caretaker finds the situation intolerable, he or she could change the situation by moving out, having their elder go to a nursing home, or asking them to move to another relative's home. Some of the people I spoke with attempted to solve their problems in this way. One man was very worried about his elderly father, who was under stress and temporarily very confused; he solved part of his problem by taking the car keys from his father for that time period.

For some people, the fear is of the unknown. For instance, a woman whose husband was ill was quite worried about how serious the illness was and how it would limit his mobility. By asking his doctor for the information and discovering the extent of the illness, she felt some relief, even though the illness was in fact serious. Another woman approached her anxiety in a very different way. She is a woman who has many responsibilities, working a full time job and caring for her children as well as for an older relative. She discovered that she felt less tense when she took a half hour between work and home to relax and be quiet by herself. Although this did not change her situation or lower the number of responsibilities, it did help her manage her level of anxiety and tension.

In a situation of caring for a person who has a chronic illness or disability, it is natural that caretakers have moments of concern about their elders, or anxiety about meeting all their responsibilities. If some of the solutions mentioned above do not work for you or are difficult to put into action, and your anxiety is greatly reducing your ability to enjoy your life, that may be the time for you to consider discussing your feelings with your physician, your minister, or with a counselor. If you would like to hear how other caretakers reduce the strain, you will find other suggestions in each of the sections in this chapter.

Responsibility

Again, nearly everyone I spoke with talked about responsibility. Some people mentioned having a high or low number of responsibilities; others talked about feeling duty-bound as opposed to not feeling a sense of duty. Most people feel that they have some responsibility for their elderly relative, but not everyone likes the word duty. To some, "duty" implies that caretaking is a negative task which they are only doing because they feel morally required to do so. Other people think of the word duty as simply another way of expressing that they feel a responsibility to help. Some people gave reasons for feeling responsible; they see it as a part of their role as a wife or a child, or due to their feelings of affection, or a way to repay what has been done for them by the elder. Some examples follow:

> "I think I owe it to him. He raised me. I think I should be giving him more time... Both my wife and I feel we owe him because eventually he's going to turn this place over to us... He's raised me; now it's my turn."

> "I'm the oldest of my family, so that's kind of built into the responsibility of the family... It makes me the head of the family for advice. It's not the neatest thing. Like when you make a decision and it's not the right one, it's -- mine. It's my responsibility..."

If you are feeling a high level of responsibility, and it is causing you stress, you may benefit by reading the suggestions at the end of the section in Independence. Many of us take on more responsibilities than we can handle well, without realizing that it may not be absolutely necessary for us to do it all.

Several people I spoke with recommend that people who are caretakers talk to the rest of their family or to friends and neighbors to find out who is willing to do what tasks, or to share the financial responsibility. It is worthwhile asking, 'Who else can I get to share the responsibilities?' A woman who is caring for her grandmother said, "I think it is important not to go over your capacities because if you go over that, I don't think you are doing yourself any good or the person you are helping any good." Setting limits can be difficult, however; you might want to discuss this with a friend or someone else who has more perspective to help you define those limits.

FEELING SAD

Almost everyone I spoke with talked of caretaking in terms of their own happiness or sadness about the situation. Some people feel good because of what they have been able to do, or because of the relationship they have with their relative. Other people feel hurt by what they see as being unappreciated by their relatives, or sad about the general situation of having a relative with a chronic illness, or unhappy about the way it has affected the relative's mood. Other studies have shown that one's physical health is closely related to how one feels emotionally. Of course, people react emotionally not only to their own health; these caretakers are also reacting emotionally to their relative's poor health as well as to their relationship with their relative. A woman who cares for her sister says:

> "When you can't seem to help, then you feel bad... It gives you a good feeling that you've helped out."

A woman helping out her mother says:

> "She goes through periods where she is very blue and she feels sorry for herself... It hurts my feelings when she talks to me in a very nasty manner."

As with the section on apprehension, there are many conditions which can cause a person to feel good or bad, happy or sad. Suggestions about how to handle difficult feelings can be found particularly in the sections on Apprehension, Conflict and Loss.

Conflict

As in any family situation, in caretaking there can be times of conflict. Sometimes the conflict is deep, underlying the very nature of the relationship between the elder and the caretaker, or between other family members. At other times the caretaker simply recognizes that there are some things people disagree about, and the disagreements happen often enough or concern the caretaker enough to mention it. Most of the people I spoke with did mention conflict in one way or another.

Sometimes the dissension or arguing was within the family; sometimes it comes from other people in the community. Some families talk about conflict in terms of how well they get along and how pleased they are that there is no conflict. Some people believe that confrontation or disagreement can be positive, while others prefer to avoid any conflict. As one woman said, "I <u>hate</u> confrontations." There is sometimes difficulty between family members when one person is the main caretaker and does more than the others; who should do what and how much? Whatever the conflict is about, it is not unusual for some to exist in any family and particularly in families where one person is the caretaker of another who is ill.

This is from a woman who is caring for her mother:

> "Some daughters just yell at their mothers... My mother will tell me she's thankful we don't yell at her like that..."

Another woman caring for her mother says:

> "I suppose there are times when we disagree on things. There are no two people who think alike on everything, but you overlook a lot of things and go on... I'll admit it isn't all sugar and cream all the way through. She'll make remarks, argumentative. I don't argue much..."

The following quote is an example of someone who values open conflict:

> "My mother and I argue sometimes, but it is better to spit it out... If we have a situation that upsets us, we'll just talk about it. Openness, complete openness... Like some people can't accept the criticism. But anybody who feels stifled builds up resentments. That's just terrible."

While it is not possible to discuss openly every small disagreement that occurs between people, it is also true that some people would prefer never to discuss disagreements they have with others. When a conflict is causing a lot of stress, it may need to be discussed openly. As one woman said, "Once you get a problem out in the open, there are solutions. But that's the hard part, getting it out." It may also be difficult deciding which things are best to open up and which things are better to gloss over. As the woman quoted above stated, "There are no two people who think alike on everything, but you overlook a lot..."

A few people I spoke with suggested that if there is much conflict in the relationship between the elder and caretaker, the caretaker simply should not take that person into their home or should avoid being the primary caretaker. While this suggestion has some merit, it is not always easy to follow. Sometimes there are no others willing to take on the duties; furthermore, in spite of conflict, some caretakers choose to be the primary caretaker (see the sections on Independence and on Guilt). It is wise to remember that there often are options. Some caretakers mentioned that they would consider turning to nursing homes if their elder's health was quite bad or if the conflict between them caused too much stress. As with conflict in any relationship, some people find it helpful to talk to friends or relatives for advice or emotional support, and some people find it useful to talk to professional counselors or ministers.

If there is conflict in your relationship with your elder, or between the elder and another member of the family, this does not mean that you should not be a caretaker. Many people provide good care to relatives with whom there is conflict.

One man who has his mother living nearby said:

> "It eliminates any strain to have her
> in her own place, her own household.
> The only thing that would create a
> strain is our clash of temperaments."

While the <u>need for space and privacy</u> was mentioned by many caretakers, it is especially important when independence is highly valued or when there is conflict between family members. With a difficult relationship, sharing the responsibilities of caretaking and perhaps reducing the time you spend with that person may make your job easier. And the more satisfied you are with your job as caretaker, the more likely you are to be able to continue caring for your elder.

Respect

The amount of esteem in which older people are held varies in different parts of the world. In some places elders are considered expendable and of little importance in their society. In other cultures, the elders are seen as the holders of wisdom and tradition, and as such are very important to their society. What is true of our country? While most of us are taught to respect our elders, there is also the view held by some that older people really have little to contribute anymore. It is often difficult to resolve the question of how one can be ill and dependent and also deserve respect or maintain pride. This concern exists for people of all ages.

About half of the people I spoke with mentioned the topic of respect in some form or another. Some of them note an increase in the~~ir own~~ self-esteem when they are able to meet anothers' needs. Some particularly recognize that other people, such as their elderly relatives, have <u>a need for self-respect</u>. A man who is helping out his uncle and respects him says:

> "He speaks to the crowd on behalf of the family... He's highly respected... The kids realize grandpa's getting old, they said, but I hope they don't make fun of him."

A man who is helping his elderly mother, and a woman caring for her mother-in-law, recognize their need to contribute:

> "I think it bolsters their ego that they've contributed, too. Like history, and language... That made her feel that she is contributing."

> "I clean her bathroom but I don't let her know I do this because I try to leave her some dignity... They have their pride... These people have got things to offer. I look to my grandpa, clear into his 80's until he got senile, he'd fish, hunt. There's just so much they can contribute."

This woman describes her own need for respect:

> "I respect my elders, but I would also like to be respected... If I were old and needed someone to care for me, I would like someone that was compassionate, did not put me down, even in non-word ways, for my inabilities, because of my age... A person has to maintain their sense of self-worth."

These caretakers are in agreement that a feeling of self-worth is important to us all. It is often difficult for those of us who are young and relatively healthy to see people we respect and care about become ill, and therefore perhaps less capable of getting around or managing their own lives. We want to be compassionate without pitying. Furthermore, the older person's illness may remind us that we also will grow old and may become ill, that we may become dependent and lose some of our capabilities, thereby raising the same questions about respect for us as for an elder. Many people do become ill and need help, yet still maintain their sense of dignity and self-esteem, which are necessary for good emotional health.

Control

About half of the people I spoke with talked about caretaking in terms of whether or not they had control over their situations. Do they have any influence? How much power do they have to affect the caretaking situation? Some people believe there is little they can do other than what they are doing already; they can provide care, but they cannot make much difference in terms of the elder's health or drastically changing the situation. Other people believe that they have a great deal of influence, or, if they do not have it now, they expect that with effort they could become more influential. Some of the caretakers want to be able to improve their relative's health, while others want to change their relative's behavior.

> "When he first got sick, he used to be so against God, because of how he was (his paralysis). I never did say anything. I tried to have him go to church because I felt maybe it would help. But I can't make him go... I thought about having our marriage blessed, but I didn't bring it up because of how he felt."

This woman is helping her husband and is accepting of her own lack of control over her husband's beliefs and actions; she may also value not intruding on his acting as he wishes. This is in contrast to the next person's ideas.

> "I was after her to go to the doctor. I wanted to make an appointment. She wouldn't go... The worst part was to get her to cooperate. It was like batting your head on a stone wall. You try everything you can to get cooperation and you can't get it... Of course, now I'm getting better cooperation."

This woman is helping her sister, and, although she is not always successful in her efforts to influence her sister's behavior, she hopes that it will be possible in the future to have more influence.

Some people are comfortable letting things fall where they may. Other people are very uncomfortable with this arrangement and want to be able to plan out their lives. Having control can be beneficial because it may result in the improvement of a situation. For instance, if your relative is ill and you believe that you can make a difference, then perhaps by actively pursuing a change (for example, taking them to a doctor) their condition may improve. However, when a situation is very difficult to change, as is often the case with people who have chronic illnesses, this attitude may lead to a great deal of frustration and stress. In such constraining situations, it may be less stressful to accept the limits of your control.

For people who prefer to have a great deal of control over their lives, this may be a difficult task. If this is true of you, it may be helpful to talk with others about your frustrations and the limits of what you are able to do. Sometimes hearing from other people that, 'Yes, it is impossible for you to change that', can give us the support we need to stop 'batting our heads on a stone wall'. Another suggestion is to continue to be involved with other activities (whether work, social or recreational) which give you pleasure, and over which you feel more in control. It may be easier to accept your limits in the caretaking situation if you are feeling actively involved in other situations.

Sometimes there do exist other plans of action which can make a difference, but the caretaker has been so overloaded and so frustrated that he or she finds it difficult to see anything else to do. One woman I spoke with, in finding out about a day health center available in her community, said, "It's a good idea, but I'll never be able to get my mother to go." With the encouragement of her family, she did call the center, and discovered that one of the staff there would take the responsibility to explain the program and convince her mother to give it a try. This approach was successful, to the surprise and relief of the caretaker.

To summarize, one of the major difficulties is in deciding whether or not there is something more you can do to better the situation. To determine this, you may need to request outside help, whether from family and friends or from a professional. In particularly difficult situations, it may be better for you to focus your goals on accepting the limits of your own control, than it would be to continue trying to change the situation. Caring for an ill person can require patience and forebearance, as caretakers themselves are well aware. As two people I spoke with advised:

> "Give yourself time to adjust. And don't give up right away. Things aren't going to solve overnight. There has to be quite a bit of give and take."

> "Be prepared that there are going to be lots of changes. It takes more time than you think it's going to take."

Guilt

For half of the people I spoke with, a typical question was, "Am I doing enough?" or, "Should I be doing something differently?" Some people ask themselves these questions, but do not have a strong sense of guilt or shame.

However, other people who express this concern feel that they might be mean or unloving people because of what they are not doing. Taking on the additional responsibilities and tasks of caretaking is usually difficult enough, but to add to that the painful feeling that they are really not doing as much as they should, only makes the situation more difficult. In a few cases, guilt is a part of the relationship between the caretaker and the elder relative and has existed for a long time. Other people recognize that if they were to do less than they are doing, as some people suggest, they would feel guilty. For people who do feel guilt, this can be a difficult balance. How much help can you provide without overwhelming yourself in terms of the number of your obligations and tasks? How much do you need to do in order to avoid too strong a sense of guilt?

One woman avoids feeling guilty by doing a lot for her mother:

> "Well, I don't regret doing it. It doesn't bother me because I feel that if I didn't help her, I'd wonder, 'well, why didn't I?' By helping her, when it is time for her to leave this world, I'll know I did all I could."

Another woman who has many responsibilities, talks about her guilt:

> "I love my mother -- and yet, many times I feel very bitter, like I'm stuck with her, and then I feel guilty for feeling that way... You have to be at peace with yourself, too. Even though I may be bitter or angry, it is not every day of my life. I think I'd feel terribly guilty if I did something else. Every psychiatrist in the world will tell you you shouldn't have guilt feelings, but if you don't live it,

> they don't know what they are talking about.. I can't help feeling guilty. I feel guilty I don't spend more time with my kids, and that I go to work. Some decisions are just very difficult to make."

This woman makes it clear that guilt is not something you can simply wish away. Although guilt is a painful feeling, and it does make the situation more difficult, several people I spoke with recognize and accept it in themselves, and are trying to strike a balance between the amount of work that they do, and being "at peace with yourself." Sometimes, just knowing that others in your situation also feel guilt can be a relief. As with other painful feelings, if the guilt feelings are so intense that you find it difficult to think about other things or enjoy your life, counseling can often be helpful.

Anger

Nearly half of the people I spoke with mentioned feeling some anger or frustration, sometimes towards their older relative, sometimes towards other family members, and sometimes concerning the community at large. It is not necessarily true that open disagreement is what leads to feeling angry, since not everyone who expressed anger also mentioned the theme of conflict. It is true, however, that anger at another person, or frustration with the overall situation, was nearly always found when the caretaker thought he or she should have more control over the situation. Anger was not expressed by the people who were accepting of not having much influence over the situation.

For example, one woman said of her sister, "I get kind of disgusted with all the money she's putting out to buy unnecessary things... It is frustrating. I'm still kind of mad." She wishes she could change her sister, but has had little success so far. Another person, a man who is helping out his elderly mother, feels irritated when his mother feels sorry for herself. One woman said that she feels furious with what she considers to be her mother's stubbornness, especially when her mother, because of her pride, will not accept or ask for financial help. These people wish they had more influence over their elder's health or behavior, and feel frustrated and angry when this proves difficult. (For further discussion, see the section on Control. The section on Loss may also be relevant.)

Loss

Since the relatives being cared for are both old and ill, it is not surprising that at least a few of these caretakers have thought ahead to the future loss of their relatives. But when people talk about loss, they often mean much more than the loss of a particular individual. Although only a few people mention this topic, for these few it seems very important. Especially when a caretaker's ethnic or cultural roots seemed especially important, this topic was mentioned. However, it may be used by other people as well. As one man said of his father:

> "I suppose I realize that when he's gone, that's it. There won't be any more home there, as far as parental home. A change from tradition... I find out things from him about the old days that have helped me to better understand myself and him, my brother and maybe my relatives in Norway."

Another man clearly explained what the loss of his relative would mean to him:

> "There are so few of us, there are so few young Indians, full-blooded Indians. I'm afraid we're a dying race... He's almost the eldest person in the Tribe we've got left... I know I'll never live the life he's lived. All the animals he's trapped and killed, all the things he's done. I take it into consideration that I'll never see those days, the days when he was young. There is so much change in the world."

Thus, the loss of an elderly family member is often not felt solely as the loss of an individual, but is also felt as the loss of a connection with one's cultural heritage. For some people, the act of caring for an older relative can also be seen as carrying on a tradition, since some groups consider caring for elders to be part of their heritage.

When people see the situation as involving loss, they may feel grief. Although people handle grief in different ways, there are some common emotional responses. Some people go through a period of time when they deny the loss, and in their disbelief, feel little emotional reaction. Most people do go through times when they feel extremely sad and at times angry about the loss. For those people for whom the angry feelings are confusing or not acceptable, they may feel some guilt at that time. However, it is important to understand that both sadness and anger are part of grieving. Acceptance of the loss does occur for most people, although it is gradual and comes sooner for some than for others, and it does not mean that earlier feelings of sadness or anger are never felt again.

Although it is expected that we grieve when someone close to us dies, what many people do not realize is that some grieving may begin earlier. When a person is elderly and is ill, or if their ability to think clearly is impaired, grieving can begin before the person dies. In some cases, the expectation of a relative's death can lead to a heightened appreciation of the elder, and perhaps of the times or culture he or she represents. For others there may be more of a sense of sadness or anger for what we are about to lose, or what we feel we have already begun to lose.

CHAPTER II

WHAT CARETAKERS DO

What do primary caretakers of chronically ill elderly relatives do? When people were asked what they provided for their relatives, they said whatever came to mind. When they were finished, I handed them a list with a number of different resources listed on it. This list covered everything from providing money or a free place to live, to doing chores around the house, providing emotional support, providing transportation, making referrals to professionals, and more. Sometimes the caretaker could only think of one or two things that they did for their elder, but after looking at the list they realized that they were doing more things. The types of help listed below are presented in order, according to which ones were provided by the most people.

Chores. Helping the elder with chores is the type of service that these caretakers mentioned most frequently. They did not need to have their memory aided by a list to know that this was one of the things that they did to help their relatives. These chores included a variety of services: for instance, caretakers help their relatives with cooking, paying bills, doing laundry, picking up medicine, doing house repairs, chopping wood, and doing the shopping.

Emotional Support. Another important service, emotional support, was not so clearly on the caretaker's minds. Only 7 caretakers thought of this on their own. The list I presented mentioned "emotional support or comfort (reassurance, company, attention)" as something that caretakers might provide for their relatives. After seeing the list, 16 said that they provided the elder with some kind of emotional support. They spoke of being patient with their elders, being loving or respectful, listening to them, and visiting them to provide them with company.

Could it be that emotional support is not seen as a resource that we provide to someone else, that is, something that is helpful to them? This is certainly possible, although many of these caretakers noted the importance of some kind of emotional support when other helpers provide it. Still, for most of these caretakers, it may be that providing emotional support is taken for granted; they may not realize how important it is to their elders.

Referrals. The third most frequently reported help is providing referrals for their elders. Caretakers help their elders to arrange for needed services or make suggestions for the care that the elder needs; for instance, recommending that they go to the doctor or call a chore worker. Few caretakers thought of this service on their own, but twice as many realized that they provide this kind of help when they were presented with the list. Again, it seems that families may not realize the importance of the help that they are providing the elders. If that is true, they should be encouraged to see this as an important service, since they are the intermediaries between their elders and the professionals. Another possibility is that families, while they recognize that this is an important service, do not consider it a difficult task or one that takes much of their time. Perhaps they take it somewhat for granted as they do the emotional support that they give.

Transportation. Providing transportation is identified as help given by most of the 20 respondents. In this case, 9 of them reported it spontaneously. This may be considered a kind of chore provided by the caretakers since it is a specific task which takes time and energy. All of the people I talked with live in a small town or rural area; it is likely that there is less transportation available for the elderly, and for everyone, in fact, than in a city or large town. However, for elders who are chronically ill, the available transportation, whether in a city or in rural areas, is probably difficult for them to maneuver. Most likely it is the family members who provide them with the needed transportation.

Concrete Needs. Of the 20 caretakers, about half provide some kind of concrete needs, such as money, housing subsidy (free rent), free food or free fuel. Someone who brings prepared meals over now and then is providing a chore, but when someone buys the groceries for the elder, then it is considered providing a concrete service. Most of the caretakers who provide this reported it spontaneously. Thus, they appear to be aware of their help and do not need to be reminded of the value of their services.

Recreation. Nearly half of the caretakers mentioned providing some kind of recreation for their elderly relative, such as helping them to get involved in a hobby or activity, taking them on a trip, or taking them on a recreational drive. Few people identified this spontaneously. As with emotional support, it could be that services that provide emotional support or pleasure to the elder are seen as less necessary. Families may also enjoy providing recreational and emotional support for their elder, but just becuase they enjoy it, or because it is not a nuisance or a difficulty for them, does not mean that they are not are no providing something of importance to their elderly relative.

Other Services. The resources mentioned above are the main kinds of help that caretakers provide to their elders. However, a few also provide personal care, such as bathing and monitoring medications, and spiritual aid.

CONCLUDING STATEMENTS

You have now had a chance to read about what caretaking means to 20 caretakers, some ways they cope with the difficulties, and a little about what caretakers actually do. As with other aspects of life (such as parenting, jobs, marriage), caretaking can offer many rewards but it also involves some stresses. Our relationships with our elders may offer us a chance for closeness, a chance to learn from someone older, and a chance to feel good about ourselves as people who can help someone in need. Caretaking relationships also add responsibilities to the caretaker daily lives, which may already be busy, or may raise conflicts about how much they are able to do or how comfortable they feel about being depended upon. When a person is responsible for a chronically ill older person, it is quite natural to wonder what might be done differently and it is also natural sometimes to feel anger, frustration or sadness.

In the earlier sections of this pamphlet, suggestions were given about talking with friends, family, counselors, ministers or physicians. Some people already talk to others about their concerns; some find it very difficult or they prefer not to. If you do talk to others and encounter some who are not helpful, you might try looking elsewhere to find people who are more understanding. As with any other situation, some people are better at offering understanding, compassion, or advice about the elderly or about caretaking than are others. Also, if you would like someone else's support or help, you may need to ask for it directly. Even when they know you are under stress, as some family members or friends may realize, people don't always know whether or not you want their help. If you want support, try asking for it, and ask before you "burn out".

It is true that if you take on too many responsibilities and feel overloaded for too long, your helpfulness as a caretaker will greatly diminish. It might not hurt to ask yourself, 'Who is taking care of me?' Most of us who have a need to give care also have a desire to receive some support and caring.

One last point is to remind you that you are probably doing more than you think. Many of the people I spoke with, as mentioned in the sections about what caretakers do, are not fully aware of how many services they are offering. Although they usually recognize that they do many kinds of chores, and provide transportation or financial help, they often fail to mention other important help they give, such as emotional support, referrals (arrangement of services), and recreation. Even though these kinds of help are difficult to measure as compared to doing chores or giving financial aid, or you may enjoy giving them, they too take time and energy and are greatly valued by the elderly who are ill. Furthermore, it is important not to discount the value of any of the services you provide. Caretakers get little recognition, except from a few family or friends, for the important work that they do. I hope that will not always be so.